


**PROCEEDINGS OF THE SECOND INTERNATIONAL
SYMPOSIUM ON VISUALLY HANDICAPPED INFANTS AND
YOUNG CHILDREN, BIRTH TO SEVEN: THE FIRST STEPS**



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P R O C E E D I N G S

SECOND INTERNATIONAL SYMPOSIUM ON VISUALLY
HANDICAPPED INFANTS AND YOUNG CHILDREN:
BIRTH TO SEVEN

"The First Steps"

SEGUNDO SIMPOSIO INTERNACIONAL SOBRE NIÑOS
VISUALMENTE DEFICIENTES DE NACIMIENTO
HASTA SIETE AÑOS

"Los Primeros Pasos"

AMERICAN FOUNDATION FOR THE BLIND
15 WEST 16th STREET
NEW YORK, N.Y. 10011

Sponsors:

The International Institute for Visually Impaired, 0-7, Inc. U.S.A.
Fundashon Arubano di Esnan Visualmente Incapacita, Aruba

Printed courtesy of
THE NEW ENGLAND
Boston, Massachusetts

ACKNOWLEDGMENTS

The papers presented in these Proceedings have been edited by the authors. A special thanks to our typists: Elizabeth Fast, Lillian Palmer and Elizabeth Parkhurst. Nydia Lopez and Edward Minderlein assisted in translations.

Proceedings Editors: Lillian Palmer
Sherry Raynor
Julie Urban

TO THE READER

The aim of the Symposium was to bring together professionals (in various disciplines) and parents in order to stimulate useful discussions on ways and means to promote child progress, share new techniques, and encourage improvement of services for young blind and visually handicapped children and their families.

The Symposium was made possible through the cooperative efforts of a great many people and agencies. We would like to express our gratitude and thanks to all the agencies and persons whose names appear on the following pages. It was their cooperative effort that made the Symposium a success.

GOALS OF THE SYMPOSIUM

1. To create an awareness of the special needs of visually handicapped infants and young children.
2. To share information on needs, problems, programs and services.
3. To develop a means of communication among professional persons and agencies.
4. To develop advocacy for visually handicapped infants and young children.
5. To promote research in prevention, intervention and adaptation.

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WELCOME

Sherry Raynor
(U.S.A.)

Good morning.

Dear friends, it's good to see you.

It has been two years since many of us met in Israel.

We have come together once again on this beautiful island to work together - to share our knowledge and our dreams for a better world for our young blind children.

Our being here has been made possible by the enthusiastic support of the island government - for which I would like to thank Mr. Bislip and ask him to convey our thanks to the others of the governing body and to all those who helped make it possible. In addition, many others have worked very hard for almost two years for this day to come about. For that, I would like to thank Mr. de Beijer, and all the workers and volunteers of the FAVI, Donna Heiner, the members of the Planning Committee, the speakers who have come from great distances, and all of you who have also come to share.

Two years ago in Israel, we had a "-Beginning-" and the results have been far reaching as people have stayed in contact with each other and worked together. Today we are here for this Second Symposium which has been named, and hopefully will allow us to begin to take, "-The First Steps-" for Parenting, Programming and Prevention. In the United States there are thousands of infants and young blind children. In the world there are millions. To serve them better, we must learn all we can and communicate that information to each other so that parents, teachers and all those working with the children will have access to as much information as possible so that these, our children, will have an opportunity for the fullest, richest life possible.

In these days of economic crises, we must find new ways to work together. With or without funds, we shall form a network of people around the world. Because it is people, like you, who make the difference in the lives of these children. All the money in the world will not help our children if there are no people, like yourselves, willing to work, seek and develop what our children need. It is the caring people that make the difference.

So this week let us join together and see what has been done and make plans for what can be done.

The little button you have in your packet represents the International Institute for Visually Impaired, 0-7, Inc. (IIVI) which is a network of people and agencies working together. The Institute is you and hundreds of others like you. I hope you will wear it with pride and become members. In this way the network will grow.

Your participation here shows a deep sense of commitment as we move on to take "The First Steps".

OPENING SESSION SPEECH OF THE
SECOND INTERNATIONAL SYMPOSIUM ON VISUALLY HANDICAPPED
INFANTS AND YOUNG CHILDREN: BIRTH TO SEVEN

Roly Sint Jago
 (Aruba)

- Honorable Lt. Governor of the Island territory of Aruba, Mr. Pedro Bislip.
- Her Excellency, the Minister of Public Health and Social Welfare of the Central Government of the Netherlands Antilles, Miss Margo Croes.
- Distinguished Members of the Program Planning Committee and the Organizing Committee.
- Distinguished Guests, Ladies and Gentlemen.

To me it's a great pleasure to welcome you here on the occasion of the Opening of our Second International Symposium on Visually Handicapped Infants and Young Children: Birth to Seven.

The history of this gathering - through the nature of its subject - is not a very long one, but nevertheless important enough to start with this morning and to bear in mind during this week.

Serving the blind and visually handicapped in some countries has been done for over a hundred years and in other countries again services are now still scarcely developed.

All over, servicing our target-group started as charity and has then gone through various stages of development, and in some countries this has finally led to institutionalization and regulation of services and social benefits by law.

Within the wide field of services to the visually impaired too there is an inequality in development, as far as the services to the various categories is concerned.

The field of services to the age group from 0 to 7 for example has our specific attention today exactly because of the fact that those of us involved in servicing visually impaired infants and young children felt a strong need for information about new concepts and about experiences from which their own work could benefit.

It is through this internationally felt lack of information on theory and practice that a movement started to organize the First International Symposium on Visually Impaired Infants and Young Children: Birth to Seven, which was held in Tel Aviv in June of 1981.

Through that international gathering which turned out to be a successful one, the need.....the need for information and contact grew even more.

As many of you present here now can recall, at the closing banquet of that first Symposium, the need for a second Symposium was voiced by many. And it was then too that I proposed Aruba to be the host-country of the second Symposium.

A great many of those present then were in favor of my proposition; however, that was not fully the case in Aruba, I found out when I got back.

It took quite some discussion before we finally decided to be sponsor because we are a rather small group already confronting a lot of work.

After deciding we would organize the Symposium together with the International Institute for Visually Impaired, 0-7, Inc., we met with the executive council of Aruba and they agreed to stand by us to guarantee the financing.

And 12 months ago we started preparing this Second Symposium, under the chairmanship of Mr. Henk de Beijer, the executive secretary of the FAVI, the Aruban Foundation of the Visually Handicapped.

The official languages of this Symposium are English and Spanish. So presentations will be done in either English and Spanish. There will be a simultaneous translation from English to Spanish and vice versa.

This has been planned in this way to participants from the whole Caribbean and Latin Area. Vingerhoedt Translations is in charge of the translations. The funding for this was made available by the Central Government of the Netherlands Antilles, through the Ministry of Public Health and Social Welfare and the Queen Juliana Fund of the Netherlands.

Finally, I want to thank everyone who in one way or the other helped to make this Symposium possible. I am sure that it will turn out to be a worthwhile investment of time, energy and money.

I wish that this Second International Symposium on Visually Handicapped Infants and Young Children: Birth to Seven will bring us a lot of new and relevant information, because anyone knowledgeable in the field of child development recognizes that the years on which we focus this week are very critical for any child's development.

Thank you!

A LAYMAN'S SHORT OPENING ADDRESS AT THE
SECOND INTERNATIONAL SYMPOSIUM ON VISUALLY HANDICAPPED
INFANTS AND YOUNG CHILDREN: BIRTH TO SEVEN

Pedro Bislip
 (Aruba)

- Honorable President of the Parliament of the Netherland Antilles, Mr. Roberto Lopez Henriquez
- Her Excellency, the Minister of Public Health and Social Welfare of the Central Government of the Netherlands Antilles, Miss Margo Croes.
- Members of the Executive Council of Aruba: Mr. Efraim de Kort, Mr. Daniel Leo and Mr. Felix Flanegien.
- President of the International Institute for Visually Impaired, 0-7, Inc., Mrs. Sherry Raynor.
- Executive Director of the Caribbean Council for the Blind, Aubrey Webson
- President of the Aruban Foundation of the Visually Handicapped (F.A.V.I.), Dr. Roly Sint Jago.
- Executive Secretary of the F.A.V.I., Mr. Henk de Beijer.
- Dear Participants, Ladies and Gentlemen.

Frankly speaking, my first reaction to the invitation of the sponsors of this Symposium to pronounce a short opening address, was one of great hesitation.

Because I thought to myself, what can I as a layman in this field, the whole field of blindness and visual impairment, tell you who in one way or the other are all experts in this field, either as ophthalmologists, psychologists, doctors of education, professors of teacher training programs, teachers, rehabilitation workers, social workers, and last but not least, parent of visually handicapped children.

What can I say that will make any sense to you, that will be of any value to you?

Honestly, I had a good mind to thank the sponsors for the honor of inviting me but at the same time I was inclined to offer my apologies for not being able to accept because it is certainly not my idea of my position, to serve as a sort of ceremonial ornament for all sorts of inaugurations.

However, considering the importance, the magnitude of this matter, whereby also Aruban parents are present amongst the attendees of this conference and since the Island Government of Aruba is partly responsible for a small number of specialized workers for the F.A.V.I., the Aruba Foundation of the Visually Handicapped and also due to the fact that some of these workers are dedicating all their time and efforts to the visually handicapped children, I decided to react positively on the invitation.

Ladies and Gentlemen,

It is really difficult to put oneself theoretically in the place of the father of a blind child.

Such situations are very difficult to imagine. You don't really know, until you are in the midst of it.

I'm afraid not even you, professionals, who have been working perhaps for many years on end with and for blind and visually impaired children and adults, really know what it means to be blind or to be a parent of a blind child.

Some of you are also parents; some of you are also blind. But even the blind adults present here, cannot really know what it means to be a sighted parent of a blind child and the sighted parent cannot really know what it means to be

blind.

A tremendous dilemma, in fact an unsolvable problem.

In spite of the intrinsic impossibility, or perhaps, precisely because of that impossibility to imagine oneself in a situation like that, I feel that I should congratulate you all, for the fact that you decided to come here from all over the world to exchange ideas and experiences, because in doing so you demonstrate there is need for more knowledge and experience.

Therefore, I congratulate you from the bottom of my heart, because you have all come here, to share your knowledge and experience.

And this is the only way in which the basic dilemma of the unimaginability of the full extent of another man's situation can be weakened enough, to facilitate a deep understanding between human beings who need help and those willing to offer help.

From this place I want to extend a sincere but strong request to you, to learn as much as possible from one another to the benefit of the visually impaired children in particular and of all blind and visually impaired and multihandicapped of the whole wide world.

And if there is one thing, that I hope this conference will do for the community of which I have the honor to be the so called first citizen, it is that it will create a general awareness of the rights and needs of the visually handicapped and by extension, of all handicapped, to be fully integrated into this community.

I am extremely grateful to the sponsors of this Second International Symposium on Visually Handicapped Infants and Young Children for offering me this opportunity and I wish you all possible success, because that success will have a deep impact, not only upon you, but also upon our whole community.

And with that sincere wish, I hereby declare this Symposium opened.

Thank you.

OPENING CEREMONY ADDRESS DELIVERED BY THE
MINISTER OF PUBLIC HEALTH OF THE NETHERLANDS ANTILLES

Margo Croes
 (Curaçao)

I must confess, ladies and gentlemen, that after the very sincere effusion of the lieutenant governor of Aruba, I feel a little embarrassed. In the first place, unlike he, I did not hesitate for one single moment, when I was invited by the sponsors of this symposium, to deliver a short address to you all.

I should really be ashamed of myself, shouldn't I? But then, also unlike Mr Bislip, I at least have some experience in the field of blindness, if it were only because I have some very good friends who are blind. In the second place, I also feel a little uneasy about the fact, that I should be the first official speaker in this important international event, because it has just been declared officially opened by Mr. Bislip.

In spite of all that, I accepted the invitation wholeheartedly, because I believe I have something important to tell you, something that has gradually become a real pain in the neck for me, in my short career as a government administrator, who wants to keep her hands clean.

Let's be quite frank, ladies and gentlemen, governments are not the most progressive institutions in the world. On the contrary. Whenever social security, welfare and health care are concerned, the first question under consideration is never the need for it, but the costs involved. If you ask me, there is something very fundamentally wrong in our attitudes towards the social problem areas in our societies. The main concern of governments, whether democratic or not, is economic power and as a result, all human activities, for which governmental involvement is required or needed, are being studied in the first place in terms of their economically beneficial merits. When a catastrophe takes place, somewhere in the world, the first thing we usually hear over the news, is the damage done in amounts of money. Only in the second place, we also get to know how many people were killed or injured.

The same thing really also goes, for the field of human activity, for which you have all come here. In the first place: why aren't there at least five hundred of you? Because of financial problems, of course. Not because the money isn't available but because governments and agency directors decided that there are other priorities than giving their workers in an important field like yours, a chance to exchange knowledge and experience.

Whenever I get any of those bulky reports on my desk, about any social problem, or about a request for government aid, the final rationale is always a financial one, and that makes me sick. Even the agencies, who apply for government intervention, invariably try to prove, that investment of financial means in their programs, is economically more beneficial, at least in the long run, than leaving the children or adults they want to serve without such services. A visually handicapped child, that doesn't get early education, will later on in life become an economic burden to society, so it is reasoned; the adult who lost his sight, will remain a burden to society if he is not rehabilitated and reskilled. The argument that any human being has a basic right to live a fully worthy life as an individual, is usually a secondary one when it comes to trying to convince a government of the need for delivering any service.

I repeat: that makes me sick..... You.... as agencies.... you know you should know that the fundamental human value cannot and may not be expressed in terms of economic benefit. Secondary concerns can never become essentials and yet, they have! If you ask me, it is not only your task to work with

might and main at the advancement of visually handicapped infants and young children, to offer them all possible opportunities to develop into fully worthy human beings, but is also essential for you, and as such, for them, to convince all those in society who have to supply the financial means for achieving that goal, that that goal alone, and not the economic benefit or loss should be the decisive argument. To adapt oneself to the existing attitudes is of course the easiest way out, but in that way, we will never change the world to become a better place for all of us and especially for your target group. Not what one has, but what one is, makes a man a man; not what one has to offer in terms of material wealth, but what one has to offer as a personality makes a human being a true and worthy human being.

I sincerely hope I have offered you something. Thank you.

K F Y N O T E A D D R E S S : T H E F I R S T S T E P S

W. Aubrey Webson
(Antigua, W. I.)

Mr. Chairman, Her Excellency, Honorable Lieutenant Governor of the island of Aruba, Distinguished Guests, Participants, Ladies and Gentlemen

It is indeed an honor and a privilege to address you at this very important Symposium. First of all, permit me to join with the foregoing speakers in welcoming those who are not from the Caribbean, to our region. Enjoy Aruba and the beauties it has to offer, for the Caribbean is like a mirror and the warmth and hospitality of the Aruban people are but reflections of the Caribbean people in general.

I bring you greetings: Organizers, Planners, Participants and Well-wishers, of this Second International Symposium, from the President, Other Officers, and Members of the Caribbean Council for the Blind (CCB) and also from its Staff at the Secretariat. My President would have loved to be here and he has asked that I wish the Symposium every success, and to make you aware of the fact that Caribbean people look forward to the fruits of this Symposium benefitting the Visually Handicapped Infants and Young Children, Birth to Seven, of our region, and also those of us working with them and in the field in general.

My topic of address - the theme "The First Steps - Programming, Prevention and Parenting". In analyzing ideas for this presentation, I felt it best to address the problem of the Visually Handicapped Infants and Young Children from its roots. In my search for facts to support my discourse, I came across a document published by Rehabilitation International, regarding the International Year of Disabled Persons, in which it is stated that 'the principle causes of disability in the world, are as a result of poverty, ignorance and inadequate social services'. It further states that 'the birth of a disabled child into a family or the occurrence of disability into a family drives that family into the morass of poverty'.

I note that the larger representation of delegates of this Symposium are from the Developed Countries and that most of the presentations are to be delivered by persons of these countries - countries which have their problems, but problems of quite a different nature to those of ours - the Developing Countries. Being aware of the existing situation in the Caribbean region, I have decided to look at the topic in the perspective of conditions within the Developing Countries, for it is estimated that over 80% of blind children in the world live within those regions referred to as the underdeveloped and/or developing countries. It is in view of this situation that I will outline what I see as our approaches with regards to dealing with the first steps in our endeavor to control or even eliminate the problems faced by the group of persons on whom our attention will be focused throughout this Symposium. Examples which will be referred to, will be related to the Caribbean region. However, I am of the opinion that related examples could be easily identified with by people from regions of the Developing World.

I challenge you my friends to look at the problems related to blindness in infants and young children, based on the realities of the existing socio-economic conditions of the countries in which these children are born. The scarce economic resources which are present have to be utilized by the Government to meet the needs of all its citizens. In view of this, I suggest that with regards to programming for the visually handicapped infants and young blind children for the delivery services, the first step must be an accurate analysis of the economic resources of the society.

In the Caribbean, (and I am sure that similar situation exists in other

developing regions) we have tried to implement programs modeled after those of developed countries, without any effort to adapt the activities to local conditions. In many cases, the result being that the programs have not been as successful as anticipated, program planners and implementers become disconcerted, thus intensifying the problem. This Symposium is therefore challenged with the responsibility of emphasizing the importance of developing programs to relate to the need of the particular community or society in which it is implemented.

At a Conference I attended a few weeks ago, a participant noted that the Caribbean people are the most 'overstudied' people in the world. He said that "one could find studies done on every aspect of life of Caribbean people..yet most of the region's problems are still to be solved". The point I am making here is that though none of these studies may be directly related to blindness, I am convinced that some studies particularly such as relate to the socio-economic conditions of our region, directly associate with many major causes of blindness. This thus points to the need for the integration of programs for the blind with already existing national and/or community programs. This approach would assist the maximum utilization of our scarce economic and human resources and should be the aim of our voluntary organizations working with the blind and visually impaired.

Programs embarked on should be used to train public health workers, teachers and such persons, to deal with the provision of services to the visually handicapped infants and young children and their parents. At the same time such programs should not be divorced from the national programs, for we want our Governments to appreciate the fact that the visually handicapped and the blind (in fact, the Disabled, in general) are not merely the responsibility of philanthropic organizations which have centered their activities on the provision of services for this group of people, but that as citizens of the particular country, they are entitled to all the rights and privileges of all citizens.

With regards to the provision of services for the visually handicapped infants and blind children and their parents, I wish to recommend that the following approaches (steps) be taken:

1. a realistic analysis of the economic conditions of the area
2. an analysis of the available resources - whether voluntary or paid services
3. an analysis of the existing programs in the territories with an aim to integrate programs for the visually impaired into national public programs
4. development of an approach regarding integration
5. appeal for the assistance of friends in the Developed World

Regarding Step No. 5, I wish to emphasize that the working relationship should be one which endeavors to provide training for local personnel. The Caribbean Council for the Blind (CCB) in one of its more outstanding programs - the Caribbena Inter-Island Eye Service - recruits ophthalmologists from Europe (U.K.) and North America for a particular period. It is not our aim to encourage this recruitment to go on forever, but we are now preparing to start a program for the training of regional personnel to equip them to handle their region's own affairs in years to come.

Mr. Chairman, Her Excellency, Lieutenant Governor, Ladies and Gentlemen....again, let me reiterate my pleasure with the fact that the organizers of this Symposium chose our region. Important, for we in the region, hope that we could be provided with suggestive approaches for facing the challenges with regards to the provision of services for the visually handicapped infants and young blind children, in the areas of programming, prevention and parenting. It is my hope that this Symposium would bring into being a greater coordination of services for the visually handicapped infants and young blind children in the Developing World.

It is my wish that when we leave Aruba, we can all voice that we enjoyed

the warmth of the Aruban people and also its climate, but more so that we can refer to this symposium as being the start to something new and dynamic with regards to the provision of services for the visually handicapped infants and young blind children.

Mr. Chairman, Ladies and Gentlemen, in concluding, I want to beg of you, that you look at the real problems of blindness as poverty, ignorance and inadequate human services - factors whose multiplier effect can be a draw-back to the development of programs for those with whom we are presently concerned. On behalf of citizens of the Developing Countries, I beg that these factors be seriously taken into consideration and that the situation be dealt with realistically aiming at formulating practicable and workable solutions.

I Thank You.

PROBLEMS OF USING ASSESSMENT INSTRUMENTS
WITH DEAF/BLIND HANDICAPPED
INFANTS AND YOUNG CHILDREN

Frieda Spivack
 (U.S.A.)

Assessment instruments that evolve from the study of the natural development of deaf/blind handicapped infants and young children while interacting with significant adults within their home/day center environment is essential. It is well known that each child, whether normal or handicapped has his/her own developmental pattern and which is influenced by genetic and environmental factors. In addition, deaf/blind handicapped infants and young children (DBHIC) bring with them special patterns of development related to their handicapping condition. Therefore, genetic, environmental and specific handicapping variables need to be investigated to understand DBHIC development.

Perhaps the most disturbing aspect in the treatment of DBHIC is the irresponsible use of inaccurate or/and morbid labels which are error laden and lead to hopeless prognosis. Also evaluation of DBHIC taken from developmental assessments normed upon a normal and/or delayed population are often useless. But professionals know little regarding developmental milestones of deaf/blind. When they encounter such a child, appropriate attitudes, knowledge and skills to properly evaluate him/her are not present.

Most assessment techniques attempt to assess a child's handicaps while observing how the handicap interferes with testing. There must be a distinction made between testing DBHIC for developmental milestones or testing for handicapping conditions.

In addition to problems of face construct and predictive validity, there arise the problems of setting equivalent age norms (BD) deaf/blind. Adelson and Fraiberg (1974) found that blind children who are otherwise neurologically and physically normal, show signs of early retardation in certain motor development of tasks based on normal age standards. The blind infant's development using motor/coordination milestones such as "sitting alone, momentarily, rolling from back to stomach, and sitting alone steadily, were the same as normal children. They were delayed in such self-initiated motor milestones such as "elevates self by arms, raises self to sitting position, stands up by furniture."

Language development may also be delayed. Piaget views language as a by-product of logic which is brought about from the general coordination of actions during the sensorimotor period. Blind infants, lacking the abundance of experiences necessary for development of operational structures, appear deficient in logical operations. This along with the lack of visual association retards the acquisition of vocabulary.

Social factors may also be affected by visual impairments. Fraiberg (1972) discussed the infant and young child's separation from the mother. Vision permits the sighted child to track his mother and see her come and go. For the blind child, if the mother is present but does not talk or move, she may no longer be in the child's field of recognition.

The problem of setting age norms also arises in dealing with the hearing impaired. As pointed out by Myklebust (1974) although a deaf person follows normal scores in sitting age, walking age, and manual dexterity, he falls below on locomotor coordination, balance, speed of motor acts, laterality and simultaneous movements. These movements demand visual-auditory associates. However, the child might be able to use other intact modalities to develop these abilities at a later age.

Acquired hearing loss during the early months of development before the appearance of language, also effects the development of communication abilities later on.

The problems of setting age norms for deaf/blind handicapped populations are intricately related to the problems of how specific impairments affect development. As previously stated, vision seems to have a central role in movement. Blindness may interfere with mobility and thus interfere with the child's capacity to explore the environment. Coordination of eye and hand is a conceptual problem for the blind child (Fraiberg). Tactile-auditory association of a person or object experienced manually is broken when the same person or object manifests itself through sound only.

Diminished language skills are a major problem for children with a hearing disability. Lennenberg, Rebelsky and Nichols (1965) found that deaf infants differ little from hearing infants in vocalization patterns during the first few months. Differences are more apparent in the last six months of the infant's first year. These differences are due in part to the lack of auditory experience. Deaf children lead more isolated lives. Inability to comprehend the affective aspects of a message that is communicated verbally are an important aspect of the poor mother-infant bond.

In selecting these and/or items to administer to a specifically handicapped child, problems arise in the selection and adaptation of items within a test. Yet to assess the milestones one must be aware of how the specific or severe handicapping condition affects development and then what should be the next step in helping the deaf/blind child's development. These latter points are not necessarily important in diagnosing the severity of the handicapping condition itself, but essential in planning for the child.

But how does one evaluate a child given his/her handicap in order to check the child's progress? One can do this only by holding the handicapping condition constant so that it does not confound the testing. This requires the creation of special developmental assessments for (DBHIC) population.

Special procedures need to be developed for deaf/blind populations which can be standardized, validated and made reliable for those populations. Rebecca F. DuBoses's studies have shown, for example, that there have been no mental measures standardized on young blind children. It is necessary, therefore, to adapt each scale so that the items can be used to satisfactorily assess the child's abilities. This presents multiple problems and greatly reduces the validity of the assessment and test results. Myklebust lists psychological tests standardized on normal populations used specifically with the hearing impaired, although Myklebust states that they are minimally valid and reliable with hearing impaired children. He explains the same task presented to normal and deaf children becomes a different problem for the deaf because of the abilities available for solving the task. Successful procedures which can be specified to be used to elicit specific developmental milestones behavior populations need to be researched.

For this reason the Assessment of Basic Capabilities, Seriously and Specifically Handicapped (ABC, SS) (Spivack '82) was designed. ABC(SS) is used as an observational and performance tool for children who are developmentally less than six months and who are visually impaired (VI), hearing impaired (HI), physically handicapped (PH), and multi-handicapped-physically handicapped retarded (MPHR). VI, HI, PH and MPHR types of handicapping conditions in a child less than six months developmental would ordinarily be difficult to differentiate from one another. This new assessment also helps the examiner examine and evaluate the difficulties the child is having in order to achieve level tasks.

ABC (SS) has face validity. It differentiates well between handicapped groups and it allows the condition to be constant in order to test the develop-

mental milestones. A facilitative intervention is used which helps the examiner and child to be able to interact with an effective stimulus. ABC (SS) has and is being used with multiply handicapped infants up until chronological age four. A paired curriculum called Twenty-five Specifically Selected Experiences for Seriously and Specifically Handicapped children is also used to develop activities and teaching strategies as a result of the child's ABC (SS) profile.

Both of the above assessments and the curriculum were developed with funds made available through Handicapped Children and Early Education Organizations, Department of Special Education and Rehabilitation, Washington, D.C.

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EARLY INTERVENTION RESEARCH ON EXPLORATORY BEHAVIOR
IN BLIND, SEVERELY/PROFOUNDLY RETARDED YOUNG CHILDREN

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In infants and young children, the acquisition of fine motor skills, such as reaching, touching, and grasping objects, is critical for the development of exploratory behavior. If a young child is blind and severely/profoundly mentally retarded, the effects of these handicaps on the development of such exploratory behavior can be severely limiting.

The single handicap of blindness can severely impede normal development. Warren (1977) states that in young blind children there is: profound and excessive use of the mouth for exploration to the detriment of the use of the hands; failure to engage in mutual exploration of two hands and failure to maintain the hands in a midline posture; excessive stereotypic behavior such as rocking, head banging, and arm waving; very late or absent creeping; and delayed walking.

Like the young blind child, the young severely/profoundly retarded child has significant delays in exploratory behavior. Moreover, the additive effects of blindness and severe/profound mental retardation further impair a young child's abilities to learn. The inability of a young, blind, severely/profoundly retarded child to reach out to objects in his/her environment or to move freely, coupled with the increased risk of developing stereotypic behavior patterns (Guess, 1966) can seriously impair the child's awareness of external stimulation and thus, independent exploration of his/her environment.

Because of the reported high incidence of visual handicaps among the mentally retarded (Ellis, 1979), and because of the lack of separate research on intervention strategies with the young, blind severely/profoundly mentally retarded child, it is critical to provide an informed research base for intervention with these children.

Authors of educational programs for the young, blind child recommend a variety of sensory stimulation activities (Barry, 1973; Fowler, 1976; Fraiberg, 1977; Mori & Olive, 1978; Sokolow & Urwin, 1976). For example, Sokolow and Urwin (1976) recommend a "play mobile" to stimulate hand movement of blind infants. Fraiberg (1977) recommends an "interesting space," such as toys on a lap tray and a cradle gym, to develop manual exploration. Unfortunately, there is no empirical evaluation of the effectiveness of these intervention strategies.

There is much more information on intervention with the young severely/profoundly mentally retarded child. That literature has emphasized the use of behavioral intervention strategies and documentation of child behavior change. Filler and Kasari (1981) demonstrate the effectiveness of parent intervention on the acquisition by severely retarded infants of six developmental tasks: visual tracking, auditory localization, rolling, reaching, weight-bearing puppy prone, and weight-bearing sitting. In their study, two parents were instructed to use a prompting and social praise procedure to increase three motor skills in each infant. The procedures were shown to be effective in a single-subject, multiple-baseline design across responses of each child. The procedure outlined by Filler and Kasari supports the use of a prompting hierarchy in which a teacher advances to increasing levels of instructional assistance, depending upon the learner's ability to respond to the task.

The present research was designed to investigate the effects of a graduated-prompting treatment procedure on the development of reach-grasp responding

in three young, blind, severely/profoundly retarded children. The experiment was conducted in three experimental phases with three single subject experimental designs (Baer, Wolf, & Risley, 1968; Hersen & Barlow, 1976).

Method

Subjects

Subjects were three blind, severely/profoundly retarded, nonambulatory male children ages 2.4 years, 2.3 years, and 4.3 years of age. Each of the three received seizure medication throughout the study. They were chosen for this study because of their blindness, their severe delay in development, and because they did not reach out and explore objects in their environments.

The first child, Ernie, was 2.4 years old at the beginning of the study. Medical diagnosis included cortical blindness, cerebral palsy and seizure disorder. The Griffiths Mental Deficiency Scales (Griffiths, 1976) showed an overall developmental age of 3.6 months.

The second child, Jason, was the oldest and he functioned at a higher developmental level than the other subjects. He was 4.3 years old at the beginning of the study. Overall developmental age, as tested by the Griffiths, was 4.5 months. Medical diagnosis included cerebral cortical atrophy, congenital blindness, optic atrophy, cortical blindness, seizure disorder, severe motor delay, and failure to thrive.

The third child, Cory, was the youngest and most severely delayed. He was 2.3 years old and was functioning developmentally at a 2.8 month old level. His records included diagnosis of congenital blindness, hydrocephaly, severe motor delay, and seizure disorder.

Setting and Apparatus

Training was conducted at each child's center-based or public school program in rooms adjacent to their classrooms. With the exception of program visitors, only the child and the experimenter were present. A VHS-video cassette recorder was obtained.

All three children were placed in chairs that most appropriately positioned them for reaching and grasping tasks. Lap trays were provided for each child. Three small squares in the midline, right and left of the center of each of the lap tray tops were designated with red plastic tape. The centers of these open squares were judged to be within arm's reach of all three children and were in a straight line. These stimulus presentation areas were used to insure the consistent placement of toys by the experimenter, who sat next to and on the right side of the child, thereby permitting convenient hand-on-hand guidance.

Three noisemaking toys were used for training: a rubber squeak toy, a bell, and a tin box with paper clips inside. According to teachers, toys selected for the study were toys the child had never played with. In addition, during the final condition of Phase 2, a commercial vibrator was used to investigate the effects of contingent vibration as a possible reinforcer for Cory.

Response Definition and Procedure

Experimental sessions were conducted daily during mid-morning and mid-afternoon by the author. Most sessions lasted approximately 20 minutes and consisted of three blocks of nine trials conducted in a randomized order at the midline, right, and left presentation areas.

The dependent measure, reaching and grasping (one response), was the percentage of trials the child extended his arm in a reach that resulted in the child's touching the toy simultaneously with his thumb and at least one other digit of the same hand for a duration of at least 2 seconds or twice by the end of a 10-second trial. It should be noted that Cory's reach/grasp met the minimum criteria for

inclusion under the above definition. Ernie and Jason, however, were more sophisticated. Both routinely exceeded those minimum criteria by enclosing the toy with their fingers and lifting it off the tray.

The independent variable was the graduated prompting procedure. Table 1 provides an outline of the graduated prompting treatment procedure for reach-grasp responding to noisemaking toys. The graduated guidance procedure consisted of criterion trials and three levels of prompt trials. A criterion trial was one in which the experimenter provided no assistance to the child following activation of the toy sound. A prompt trial was one in which the experimenter provided one of three levels of assistance: verbal prompt, tactile prompt, and direct physical guidance. If the child emitted a reach/grasp response on a criterion trial, the response was counted as correct. A reach/grasp response to any of the three kinds of prompt trials was an assisted response, and was not counted as a correct response.

Throughout the study and during all trials, the children received social praise and the naturally-occurring opportunity to manipulate the toy contingently upon reaching and grasping. Social praise consisted of statements such as, "good boy, you got the toy!" paired with physical contact in the form of hugs, pats, and kisses. Once the child reached and grasped the toy he was allowed to play with it for an average of 30-40 seconds.

Interobserver Agreement

During the session, the experimenter recorded on a data sheet the occurrence and nonoccurrence of the reach-grasp responses. The experimenter videotaped approximately half of the sessions. An independent observer recorded, on a data sheet, the child's reach-grasp responding from the videotapes at a location other than the school site. Throughout all three phases interobserver agreement was exceptionally high--93 to 100% agreement for all three children for both occurrence and nonoccurrence of the reach-grasp response.

Results

Three single-subject experimental designs were used in the three phases of the experiment. Phase 1 was designed to answer the question whether the graduated-prompting treatment procedure was powerful enough to increase reaching/grasping by three different subjects. Figure 1 illustrates the percentage of trials in blocks of nine trials, in which each of the three children independently reached and grasped a noisemaking toy across experimental conditions during Phase 1. Prior to training, none of the children independently reached and grasped a toy within 10 seconds. When the graduated-prompting treatment procedure was introduced, reaching-grasping increased above baseline levels for each of the three children.

Ernie and Jason showed clear and significant improvement in independent reaching-grasping in response to toy sound. Cory showed smaller but nonetheless important gains during the treatment condition. No generalization from training at midline was observed in the right and left positions by any of the three children.

Phase 2 was designed to answer the question whether Cory's small treatment gains would be maintained in the absence of the treatment procedure, and secondly, whether the addition of vibration to the social reinforcement event would promote further gains in the effectiveness of the treatment procedure. Thus, Phase 2 consisted of a repeated reversal design. Figure 2 illustrates the percentage of trials in which Cory independently reached and grasped a noisemaking toy in Phase 2 across six experimental conditions. Independent reaching and grasping toys did not occur in any of the baseline blocks of trials.

When Cory received the graduated-prompting treatment procedure, the percentage of reaching-grasping responses 0%. Although Cory's performance during treatment showed positive change over the baseline conditions, it was not clear whether the reinforcement procedure could be made stronger for Cory's independent

reach-grasp responding than for prompted reaching-grasping. To assess that possibility, in the final condition, Cory received the graduated-prompting treatment procedure and contingent vibratory stimulation was added to the social reinforcement component of the procedure during criterion trials. There was no significant change over the other treatment procedure.

Phase 3 was designed to answer the question whether the graduated-prompting treatment procedure was powerful enough to produce reaching-grasping at the right and left sides of a lap tray, as well as at midline. Also in Phase 3 it was asked whether a shift of stimulus control from toy sound to voiced instruction alone would occur. Thus, Phase 3 consisted of a multiple-baseline across lap-tray positions. Figure 3 illustrates the percentage of trials in which Jason reached and grasped a toy across the midline, right and left positions on the lap tray during the baseline and graduated-prompting treatment conditions of Phase 3.

The systematic introduction of the graduated-prompting treatment procedure across midline, right, and left positions was associated with clear and significant improvement in reaching-grasping responses to toys sounds. There was also savings over time in the number of trials to criterion performance of the treatment procedure.

Figure 4 illustrates generalized effects of the graduated-prompting treatment procedure to a new situation in which toys were presented silently and the experimenter merely told Jason to find the toy. During baseline, Jason never reached and grasped toys presented silently following a verbal instruction, except for three blocks on the left. The introduction of the graduated-prompting treatment procedure with toy sound available at the midline, right, and left positions, as shown in Figure 3, was accompanied by an increase in reaching/grasping during voice alone probe trials shown in Figure 4.

In summary, it was clear that by teaching Jason to reach and grasp toys that made sound, in the midline, right, and left position, he could, without additional training, perform reaching and grasping responses in all three positions when verbal instruction was the only prompt for responding. Shift of stimulus control from toy sound to voiced instructions occurred in Phase 3.

Discussion

This experiment provided support for the literature indicating that a graduated-prompting treatment procedure can be effective in training motor skills with the severely/profoundly retarded individuals (Filler & Kasari, 1981; Gold, 1972; Lent & McLean, 1976). The present study extended that finding to a new population of children; young, retarded children who are also blind. Such children are frequently inactive and unresponsive to external stimulation, and they often engage in stereotypic behavior. Teaching them to reach-grasp objects in space close to them would appear to be one of many prerequisites enabling such children to explore their environments more routinely and more independently.

Furthermore, in the present study, graduated prompting was shown to be an effective procedure without use of extraordinary reinforcers. Social praise, hugs, pats, kisses, and naturally-occurring toy manipulation were available throughout all baseline conditions as well as during the treatment conditions. Indeed, this procedure was used because of its ease of administration and was easily taught to the teachers at the end of the experiment.

The graduated-prompting treatment procedure may be appropriate for normally-developing, as well as for handicapped children. In fact, the procedure as described would appear to be ideal for nonretarded blind infants and pre-schoolers. The need for such a program was indicated by Fraiberg (1977) whose descriptive research delineated the kinds of developmental delays shown by blind infants.

Furthermore, according to Fraiberg, the ability to reach and grasp following the onset of sounds may later serve as a "lure" for the blind child's gross motor movements of creeping and walking. If it is true that a blind child reaches and impasse in development because he does not understand the association between sounds and objects, then his development can be enhanced through the use of these procedures.

Further study of the specific technology used in the present research is needed. Systematic replication with more children would enhance the generality of the findings. A component analysis of the treatment procedure used in all three phases of the experiment would evaluate the separate contributions of each element of the procedure. Furthermore, generalization to different environments and the maintenance of the treatment effects over time require further study.

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Table 1

Graduated-Prompting Treatment Procedure for Reach/Grasp
Responding to Noisemaking Toys

Type of Trial	Experimental Procedures at Graduated Assistance Steps	Child's Response by Level of Assistance
Criterion	Step 1--No Assistance. Present toy, produce toy sound. If reach/grasp occurs, reinforce. If no response in 10 seconds, go to next step.	Level 1--Independent response (correct response)
Prompt	Step 2--Give verbal prompt: "(Name), get the toy, it's in front of you." Produce toy sound. If reach/grasp occurs, reinforce. If no response in 10 seconds, go to next step.	Level 2--Prompted response (assisted response)
Prompt	Step 3--Take child's hand and place on object for 5 seconds, return hand to original position. Produce toy sound. If reach/grasp occurs, reinforce. If no response in 10 seconds, go to next step.	Level 3--Prompted response (assisted response)
Prompt	Step 4--Take child's hand and give direct physical guidance in reach-grasp behavior. Produce toy sound. If reach/grasp occurs, reinforce. If no refusal, end trial and begin at Level 1. (There were no refusals.)	Level 4--Hand-on-hand guided response (assisted response)

FIGURE 1

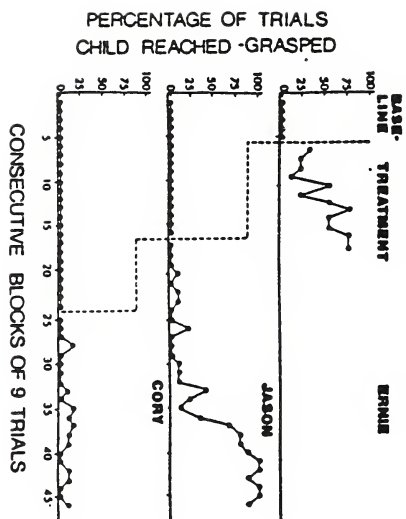


FIGURE 2

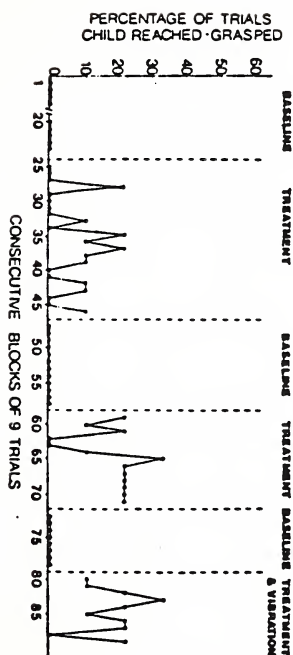
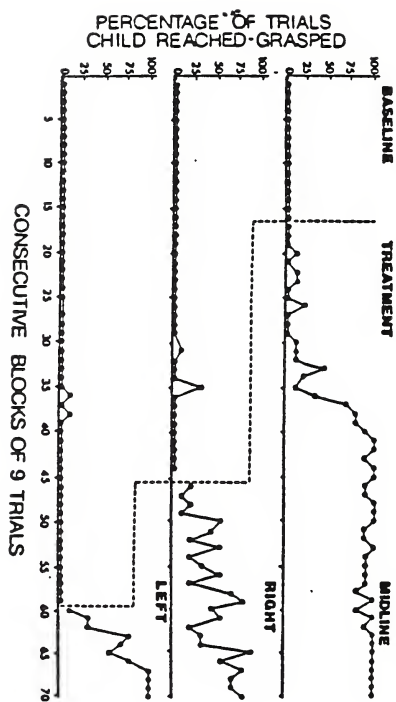


FIGURE 3



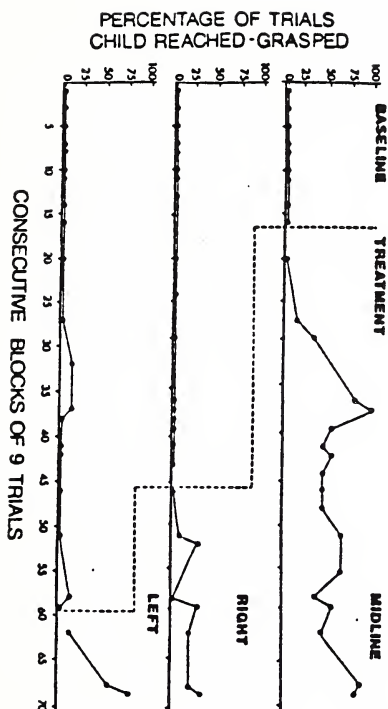


FIGURE 4

PREVENTION OF CONDITIONS WHICH IMPAIRS VISION AMONG INFANTS AND PRESCHOOL VISUALLY HANDICAPPED CHILDREN IN NIGERIA

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Unlike what is obtainable in most developed countries of the world, services for parents, infants and preschool visually handicapped children are very inadequate in developing countries. In most places they do not exist at all. Yet, one would like to believe that, of all the five senses, sight is the principal one, the one that each one of us would like to keep throughout the course of our lives. The loss of sight is one possession no one would wish for himself or anyone dear to him. Yet sight is treated by most people with such carelessness as though it is a common possession, one which can easily be replaced.

Most of the causes of visual handicaps among children in developing countries are preventable. Dr. Halfdan Mahler, the director - general of the World Health Organization stated in one of his addresses, that throughout the developing world, two thirds of cases of blindness are estimated to be preventable and curable. If this be the case, it becomes imperative to work towards prevention of blindness. The closest people to any child is the immediate family. They come in contact with the child before anyone else and the children spend most of their lives with their parents. The family influences him for good as well as for evil. Parents generally do not want any evil to befall their child; they wish the best for him. For parents, however, to give the best to their child they must have the knowledge of what to give and how to deliver it. Most parents are ignorant as to what to do for their child before his arrival and what to do after he arrives to keep him healthy and strong.

There is, therefore, a need for programs for parents. This training should start with couples searching for a child.

PRENATAL PERIOD

Parents, especially young parents, need to be prepared adequately on the family life. Having a healthy strong child is a wish every young parent wishes for. In developing countries, where maternal and child care services are not adequate, natal and post natal factors increase the total number of victims. Primary Health Services for prevention of handicaps are possible if particular factors are identified through screening exercises. Studies reveal that about 15 per cent of women of childbearing age have not developed natural immunity against rubella infection. If such women should contract rubella in the early months of pregnancy, the rubella virus will undoubtedly cross the placenta and cause considerable damage to the fetus.

No doubt, in many industrialized countries, it is recommended that routine immunization of infants or school girls against rubella, be a common practice. This practice is uncommon in developing countries. It is recommended that young women be advised therefore that, before they embark upon pregnancy, it is important to take a simple blood test which can reveal as to whether she is immune or vulnerable to rubella infection. If it is found that she is vulnerable, immunization can be undertaken. In this way, any risk to the unborn child, should the mother come in contact with rubella during pregnancy, is eliminated.

Also, in these counselling centers, young ladies about to be pregnant could be advised on the importance of good balanced diet for proper development of their child. Children have been born with cataracts, this is an evidence of poor maternal feeding at pregnancy and an evidence of deficiency in Vitamin A.

One other important factor, that parents have to be counselled upon, is the need of ascertaining that the mother of the young baby to be born has no Gonococcal infection of any sort. Should any infection be suspected, this should be cleared before the arrival of the child. Most often, babies get the disease during the birth process. The need for counseling centers for young mothers cannot therefore be over emphasized.

For any well coordinated nation-wide program on prevention of blindness to operate adequately, it must be supported with properly trained personnel and a good financial support is indispensable. Furthermore, the individuals in the community have to be involved in the program. A good program on prevention would involve three primary phases which are as follows:

THE PRIMARY EYE CARE PHASE

In this stage, the local population should be involved in the appropriate services for common eye conditions. Screening has in the past few years become a major preventive function within all national health services in several countries. Screening, particularly in the developing countries is used clinically to identify preventable disorders. Screening is also important in that it leads to the control or to minimize the potential ill effects of an established disorder at an early age, before the condition becomes unresponsive to treatment.

A major service that is recommended for preschool children and infants therefore is eye-screening. This can be done in schools or Health Centers. Early detection and treatment of visual defects will go a long way in preventing blindness significantly. Cochrane and Holland (1971) have pointed out that before a screening procedure can be justifiably introduced on a national basis for clinical purposes, it is necessary to show that:

- 1) The disorder which the screening procedure identifies is one of which treatment of proven value exists and is readily available.
- 2) The screening test is itself reliable, without an excess of false negative or positive results.
- 3) The screening test is simple to apply on a universal basis and acceptable to those to whom it is administered.
- 4) The cost of the screening test is one which is financially acceptable. This means that some tests which may possibly provide some benefit at considerable cost for relatively few people have not been considered to have justified their inclusion in a national screening program.

Simple screening exercise can easily be conducted by regular classroom teachers and the school nurse. For children who can read the letters of the alphabets, their distance vision can be tested from an ordinary Snellen card. Before the child is capable of reading, he can be given the "E" test which only requires the child to point to the direction in which the letter "E" is pointing. In addition, the child could be required to perform various activities, such as matching of symbols, discriminating objects of various sizes and colors. Children, who indicate signs of eye defects, are then referred to an eye specialist for a more thorough diagnosis and treatment.

Treatment should be made available for such common eye conditions as conjunctivitis, superficial foreign bodies in the eye, trachoma, etc. In Nigeria, as in most other developing countries, treatment for the above diseases are not readily available to the public. Until this condition is improved, eye disease will continue to be on the increase. It is essential that primary health workers be made available to the people in the community. These workers should be provided with essential drugs for treating eye diseases. Drugs such as topical antibiotics like suphacetamide, tetracycline, chloramphenicol could be supplied to these

workers. Community sanitation and personal hygiene could be promoted by teachers, social workers and dieticians. Ocular health education could be promoted.

This primary health care has, however, started in some parts of Nigeria, but the services are still restricted to some small sections of the country. More of these services need to be made available.

SECONDARY HEALTH CARE

Secondary Health Care services are vital services that should not be dispensed with in any community, particularly in developing countries. This should be centrally located in the community for easy accessibility to the people in the community.

Of great importance, adequate arrangement for proper care should be made for children affected with measles and those found deficient of Vitamin "A".

Well organized, hospital based mobile clinics could be used for delivery services to those in areas far away from hospitals. Although such secondary Health Services do exist in Nigeria today, the number is still very inadequate in a country with a population estimated at 80,000,000 inhabitants.

TERTIARY EYE CARE

The need of establishing tertiary eye care units in the various regions throughout the country cannot be over stressed. These could be established where there are medical schools. As of now there are not less than eight of Nigerian Universities with medical schools. Many more of these universities run nursing schools as well.

In such centers, provisions for sophisticated eye care such as corneal transplantation, retinal detachment repairs and other complex and expensive forms of treatment which the secondary eye care unit cannot perform should be made available. Their clinical expertise should be used in order to generate staff who would serve in the primary and secondary eye care units of the country.

The staff whose responsibility would be to run and coordinate the mobile clinics to the hinterland communities would come from these tertiary eye care centers; they should be taught the need for continuity and follow up of such mobile clinic programs.

Most importantly, the training programs for staff should be such that meet the needs of the people. There should be emphasis on ophthalmology in the curriculum of undergraduate medical students. Post graduate doctors should be active participants in field activities. This activity will go a long way to high-light preventive ophthalmology.

As of now, there are some tertiary Health Care Centers in Nigeria, but are not adequately supported in terms of finance and staffing. In the clinics in Jos, for example, according to Professor Oji, the Head of the Units, seventy thousand patients are seen yearly. These include adults and children of all ages. Surgery is performed on about 10 to 15 cases of cataracts weekly. The training of primary health workers in ophthalmology is going on as of now in these centers and graduates are sent to sub-clinics and district hospitals to work while they continue to maintain links with the Tertiary Health Care Unit.

CONCLUSION:

In addition to the primary, secondary and tertiary Health Care Centers mentioned above as approaches to preventing blindness in Nigeria, the government also should take a more positive part in eliminating those agents that contribute to eye disease such as onchocerciasis.

The need for a cooperative effort to prevent trachoma, for example, cannot be over-emphasized. This can be prevented by keeping homes and environments

clean. Trachoma thrives in dirty and overcrowded environments. Avoiding of overcrowded environments is therefore important if trachoma is to be eliminated.

Finally, the Nigerian Health Authorities should make it their responsibility to see that the Nigerian people are well instructed on better health care and health habits. In the villages, where the masses cannot be reached through the Mass Media such as television, the health authorities, social workers, teachers and all those concerned with the welfare of the blind should make all efforts to organize lectures on health habits, and care for the people in their various communities. This can be carried out in market centers, village halls and churches.

If these recommendations are taken, most eye defects among our children would no doubt be prevented, and the number of young people going blind would be on the decrease.

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OPHTHALMIC DISEASES AFFECTING PEDIATRIC AGE GROUP
IN THE CAYMAN ISLANDS

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Cayman Islands is a group of three islands situated to the south of Cuba with a population of about 15,000. The Ophthalmic Services are managed by a resident Optometrist and a visiting Ophthalmologist from Jamaica.

The common ophthalmic problem seen in the pediatric age group are:

Infantile Cataracts
Retinitis Pigmentosa
Allergic Conjunctivities
Squints

In this paper, emphasis is given to the management of the Infantile Cataract and Retinitis Pigmentosa.

INFANTILE CATARACTS

The management of cataracts in infants and children has been a problem to all ophthalmologists, but the recent advancement in the diagnostic investigative and operative techniques has facilitated in its early detection, prompt treatment and a good visual improvement after surgery. Even with all the improvement in the technicality of the management, the visual improvement after surgery is disappointing.

In the case of a Senile Cataract, the visual function of the eye is known prior to the cataract formation, but it can still be determined with a complete cataract by the color perception and two point discrimination, but, in the Infantile Cataract, there is no prior visualization of the posterior segment of the involved eye, and this gives a dilemma whether to operate or not.

The time of surgery is very important in an Infantile Cataract. Mary et al have demonstrated that visually evoked response of infants attain potential waveforms equal to the adult by the age of six months. They have shown that the retina and the visual cortex have the potential at that age to see as well as an adult, Hubel and Wiesel, and Von Noorden, have shown that visual deprivation can produce permanent amblyopia. The agreed time is that the Infantile Cataract must be removed before six months.

Roger et al (1981) proved that the visual improvement was best when surgery was done before eight weeks.

The Infantile Cataract can be classified according to the morphology or etiology.

Morphology

1. Polar Cataracts
 - (a) Anterior
 - (b) Posterior
2. Zonular Cataracts
 - (a) Nuclear
 - (b) Lamellar
 - (c) Sutural
 - (d) Stellate
 - (e) Filiform
 - (f) Coroliform
3. Total
4. Membranous

In this Study, out of 36 cases: Total = 26; Aut. Polar = 3; Consular = 7.

Etiology

1. Sporadic
2. Hereditary (auto somal, regular transmission)
3. Cataract (as a part of Systemic Disease)
4. Cataract (secondary to an eye disease)

In this Study, sporadic cases were 17; Hereditary 10; Cataracts due to systemic disease 6; Cataract Secondary to Ocular disease 3.

Management

The management of any infantile cataract depends on whether it is bilateral or unilateral, or whether it is complete or incomplete. Before the surgery is attempted, a complete examination of the eye is done including the following: (1) Anterior Segment examination (Slit-lamp) (2) Pupillary Reaction (3) Visual attention by the child (4) Posterior Segment examination after pupillary dilation (5) Recording Visual acuity

Bilateral Complete Infantile Cataract

These patients usually come to the attention of the Ophthalmologist because of the presence of Leukohoria, lack of attention. In these cases, surgery is recommended early. One eye is operated on first, followed by the other eye after four weeks. Later, glasses or contact lenses are given, and, if the child has amblyopia, occlusion is administered. In this series, 160 of them had surgery in the category, and all of them are wearing glasses.

Bilateral Incomplete Infantile Cataract

In these cases, evaluation of fixation and behavioral pattern determines the need for surgery if the lenticular opacity is small, the pupillary dilation and corrective glasses is given (Constenbader et. al. 1957).

During each follow-up, the density of the cataract is assessed. Surgery should be undertaken when the best corrected visual acuity falls below 20/70.

In this series, 9 patients, who had incomplete cataract, have been followed up for 3 years, and only 3 cases had to be subjected to surgery.

Unilateral Complete Cataract

Indication for surgery in patients with unilateral complete cataract remains highly controversial (Binkhorst C. D. et. al. 1964, Constenbader et. al. 1957, Francois 1973, Van Balen 1973). The visual improvement in these patients is unsatisfactory due to the associated and anatomical ocular defect, and in addition, there is high incidence of amblyopia and strabismus. If the surgery has to be done, it should be done before the age of three years, and the only advantage of surgery in these cases increase the peripheral vision. In this series, 3 eyes have been operated on, and 2 have not been operated on, because of late detection of cataract.

Unilateral Incomplete Infantile Cataract

In the case of Unilateral Incomplete Cataract, it is better to dilate the pupil and improve the vision with the glasses. Most of these cases do not improve after the surgery because these cases come late to the Ophthalmologist. We have six cases in this series who have Unilateral Cataract who are using glasses for the last 3 years.

After the surgery in any of the above categories, the patients have a choice of either glasses, contact lenses or intraocular lenses. The glasses are suitable for older children, but the glasses are an imperfect optical solution to aphakia, because of alterations in the peripheral field of vision, induced distortions and increase in the retinal size image.

Contact lenses provide unrelatively good vision, this should be given in 2 age periods, called the golden ages. The first, between birth and approximately the second birthday. During this time, the infant is unable to resist contact lenses insertion effectively. The second period is the age 6 years and above. The other factors which should be considered, are the maturity of the child, the environment of the child, and the motivation of the parents.

In children whose visual acuity is sub-normal either with or without, surgery should be subjected to the use of low visual aids.

RETINITIS PIGMENTOSA

This is a degenerative condition of the retina progressive nature associated with night blindness which is hereditary and familiar in its incidence. The main problem in this disease is the affection of rods and cones of the retina.

The hereditary of the retinitis pigmentosa can be autosomal recessive, autosomal dominant or sex-linked recessive. According to Frank Cois, 20% of cases are inherited as autosomal dominant, 37% as autosomal recessive and 4% as sex-linked recessive and 39% arise spontaneously without any previous family history of this disease. The autosomal dominant form is milder and its effects slower. In the sex-linked type, the female transmits the disease and male manifest the disorder and it is very rare.

The main complaint is difficulty in dark adaptation in most patients. This symptom dates back to early childhood. Visual acuity is not affected till adolescence as the the disease progresses, there is a constriction of the peripheral field and in advanced cases the field becomes tubular. The last stage of the disease is complete blindness.

The main diagnosis is by ophthalmoscopy, electroretinography, electro-oculography and field examination.

In this series, 9 families, who had a family history of retinitis pigmentosa, were examined. Each family underwent an ophthalmoscopic examination and a field examination. E.R.G. and E.O.G. could not be done due to lack of facilities. 5 children, who showed pigment changes in the fundus, are being followed-up for the last three years. (between 7-9 years)

There is no treatment available for this condition. Education, marriage counselling and rehabilitation are the three methods by which we can tackle this problem.

SQUINT

Forty six (46) cases of squint were detected in the last 3 years. The treatment instituted were occlusion in 10 and surgery in 36. 20 cases were bilateral while 16 were unilateral out of the 36 cases. 23 were operated for convergent squint and 13 for divergent squint. The major problem being faced in the Cayman Islands is late arrival to the Ophthalmologist because of lack of education and reluctance on the part of the parents.

REFRACTIVE ERRORS

408 patients were referred to the clinic from the school health program out of which 236 were myopic and 252 hypermetropic.

ALLGERIC CONJUNCTIVITIS

231 children have been treated for this condition and the probable causative factor being dust and pollution.

CONCLUSION: In the Cayman Islands, both genetic and other factors play an important role in the various diseases seen in children and affective medical attention, both therapeutic and educational are being instilled effectively.

EARLY INTERVENTION ORIENTATION AND MOBILITY PROGRAMMING:

A DEVELOPMENTAL/HABILITATIVE PERSPECTIVE

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Orientation and mobility training, the term used to describe those instructional methods employed to help individuals move independently, safely, and purposefully through the environment, has traditionally provided visually impaired persons with techniques to help compensate for the visual loss while negotiating the environment. Established rationale for provisions of orientation and mobility (O&M) training for adult visually impaired individuals focused upon the loss of mobility as one of the three primary losses a newly blinded individual experiences (Lowenfeld, 1948). It has been widely accepted that:

Mobility represents the avenue through which a person who is born blind or becomes blind at a later age, reaches out into his social, educational, vocational, and economic environment. Without mobility, successful integration into the community and independent functioning are blocked. (Wilson, 1976, p. 287)

As locomotion and navigation through one's environment utilizes primarily the distance sense of vision, it seems apparent that those persons not able to draw from this sense must employ other means through which such locomotion can be made possible.

A historical perspective of the field of orientation and mobility is valuable for an understanding of the evolution of current programming philosophies, methodologies, and controversial issues in the field today. O&M, as known today in its formal terms, broached the field of "blind rehabilitation" following the second World War. With the sudden influx of newly war-blinded veterans returning to the United States, a formalized O&M program was developed to meet their rehabilitative needs. In 1960 the Vocational Rehabilitation Administration funded the first university training program for Orientation and Mobility specialists, utilizing many of the methodologies devised in the 1940-50's. Although the training was adult oriented, some of the first graduates were employed by residential or public schools serving visually impaired children. With the founding of these first formal O&M training programs for school-aged students heightened interest was given to providing programs specifically designed for children. The awareness of concept development in the late 1960's helped foster three dimensions of O&M training for the students: 1) concept development, 2) pre-cane skills, and 3) cane instruction.

Funding for university programs training specialists to work with school aged children was first appropriated by the Department of Health, Education and Welfare in the late 1960's. However, typical methodologies continued to reflect the rehabilitative approach. "Rehabilitation" in formal definition refers the "action or process of restoring to a former capacity" (Webster, 1977, p. 974). However important the rehabilitative philosophies are to adventitiously blinded adults and older children, it has not always met the educational and travel needs of the younger and/or multihandicapped child.

Today the incidence of visually impaired preschool children in the United States has reached astounding figures. This increase is due, in part, to more sophisticated census reporting, public awareness, and improved technology for early diagnosis rather than actual increase in numbers. In essence, young children who may not have been diagnosed as having a visual impairment in former years are now being identified. Current estimates of preschool-aged visually impaired

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children in the United States vary from source to source. However, despite the number of inconsistencies, it is evident that there is a significant population of young visually impaired children. The National Accreditation Council's 1979 edition of *Preschool Services (0-6)*: Section D-15 reports an estimated 20,000 visually impaired preschool (birth to under six years of age) children in the United States. In their 1980 text, *Vision Problems in the United States*, the Society for the Prevention of Blindness reports that one out of every 20 children, ages three to five, has a vision problem. The range of these ocular problems include correctable refractive errors to serious visual impairments. Graham (1966) states,

Blindness is a function of population: the more children that are born, the more blind children there will be. Incidence rates may decrease as medical science advances but absolute numbers of blind children will not. (p. 19)

Credibility is given to Graham's statement not only by the mentioned prevalence data, but especially by statistics related to the developing countries of the world where the population growth is rampant and persons are further susceptible to blindness due to poor nutrition, sanitary conditions, and lack of medical facilities.

Included in the vast numbers of children who are reported as having a visual impairment are those children whose visual impairment is just one of their handicapped conditions. The issue of visually impaired children with concomitant disability(ies) is not a recent occurrence. Barraga (1976) contends:

Visually handicapped children who have impairments in other body systems are not a new subject, but in the last few years, so-called multihandicapped children have received greater attention. (p. 35)

Although such children existed prior to the 1960's, including those from the retrolental fibroplasia (RFL) crisis, the widespread rubella (German measles) epidemic of 1963-65 caused the percentage of multihandicapped blind children to increase drastically. Lowenfeld, in his 1973 text, predicts that even after the 1980's when the multihandicapped RLF and rubella epidemic persons are beyond public school age, the incidence of multihandicapped visually impaired children within the school-aged population will still be significant.

Today with the increased emphasis given to early intervention and/or multihandicapped programming, the field of O&M has needed to reevaluate its training strategies to serve the needs of these populations. A survey of United States O&M Specialists was conducted through the University of Northern Colorado in the spring of 1982 to assess attitudes, philosophies, and needs of the then current O&M programs in the areas of concept development and training for visually impaired, birth to five, and/or multihandicapped students (Anderson-Wright, Anthony, Gense, 1982). Results from the survey implied a clear two-fold message: 1) the need to serve the stated populations was highly recognized, and 2) the majority of the respondents felt insufficiently trained to serve the stated populations.

The traditional definitions of "orientation" and "mobility" must be further clarified when addressing the needs of birth-five and/or multihandicapped visually impaired children. "Orientation" has been typically defined as "the process of utilizing the remaining senses in establishing one's position in one's environment" (Hill, Ponder, 1976); "Mobility" as "the capacity, the readiness and the facility to move" (Hill, Ponder, 1976). From the moment of birth, a child begins the process of developing purposeful movement, a process contingent upon both cognitive and motoric growth. "Orientation" can be considered the cognitive component, "mobility" the motoric, in their interdependent relationship of the development of purposeful movement.

Classical developmental theory purports the growth of the cognitive and motoric functions as beginning at birth and evolving through a sequential process in which opportune learning readiness periods are evident (Illingworth, 1970;

Kephart, & Godfrey, 1969; Piaget, 1967). It is imperative to establish the bases of cognitive and motoric development when planning and implementing an O&M program for the birth to five and/or multihandicapped visually impaired populations. Philosophical support of the direct relationship between the functioning of the body and that of the mind has been suggested throughout history from psychologists, theorists, and educators. Little was done, however, to lend empirical or statistical evidence to such a relationship prior to the 1960s. Previously, the motoric functions and cognitive development were generally treated in isolation with minimal support given to the interrelationship of the two.

With acceptance of orientation and mobility as analogous with cognitive and motor development, and with the understanding that a visual impairment may considerably alter a child's progression through the developmental milestones (Adelson and Fraiberg, 1972; Fraiberg, 1977; Wills, 1970), it is logical to advocate an early intervention O&M program reflective of a developmental philosophy. It is logical to assume that early intervention orientation and mobility training may aid in alleviating some of the typical problems relating to concepts and movement qualities often observed in the developing visually impaired child. Additionally, early intervention O&M may well enhance areas which have typically been noted as problem areas for school-aged visually impaired children, including posture, gait, abnormal movement qualities, limited body image and spatial concepts, etc. A habilitative orientation and mobility approach is a new perspective from which parents and professionals can view training for the visually impaired child. This habilitative approach encompasses the total child, beginning as early as the first months of life and meeting educational and travel needs in all facets of development.

Considerations for early intervention, habilitative orientation and mobility programming may include the following key point:

- Early intervention O&M is not the exclusive responsibility of the O&M Specialist; it includes both the parent(s) and the team of professionals involved with the child. While each professional has an area of speciality, the approach should be team oriented with overlapping goals and intervention strategies.

- Each child is an individual and should be viewed as such. The child also should be considered as a "total child", with program emphasis encompassing all behavioral areas. Developmental readiness, regardless of chronological age, should be assessed and considered when devising programs.

- The primary objective of early intervention O&M programming is to encourage optimal independence for each child, regardless of functioning and/or age level.

- Natural learning situations should be incorporated with an emphasis on the child's own responsibility to move as opposed to rote movement situations. Movement is an important learning modality as it can help define the child's environment, connecting the "self" to "non-self" through spatial explorations/experiences.

- Intervention strategies should include a realistic base, involving authentic life experiences in a normal environment. It may be appropriate, in some instances, to modify the environment in order to enhance the learning situation(s) and help provide the child with increased information from the environment.

- Cognitively, the child needs to move from concrete to abstract and instruction should facilitate this structure.

- The development of a sound body image is necessary before the child can be expected to make complex judgements involving space. Therefore it is important to teach the child about his/her own body before expecting the child to understand spatial concepts.

- Motivation facilitates movement. Those involved in early intervention O&M need to incorporate activities and situations which are personally motivating to each child.

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MOVEMENT IN THE CONTEXT OF A LEARNING FOR LIVING PROGRAM

MUIRBURN LODGE UNIT FOR MULTI-HANDICAPPED BLIND CHILDREN, EDINBURGH, SCOTLAND

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Movement has, for some years, become a growing interest in Muirburn. It wasn't that we failed to recognize its importance before, but rather that our procedure was too haphazard. At last, things were beginning to come together, forming a whole package of related activities to which the children responded. We felt that we had, at least, some of the components right, and had established a base line from which individual children could begin to move forward. It was a program they clearly enjoyed and it had an end product, which was meaningful for everyone, no matter how handicapped.

For a long time, we had worked individually with children on body image, getting the children to know their body parts and recognize their names; also painstakingly, we had worked on the language of spatial relationships - what we mean, for example, by "in and out", "over and under" (not easy concepts to teach mentally handicapped blind children); and, finally, we had spent time on the language of movement itself - "running" and "jumping", "forwards and backwards", and so on. Traditional rhymes were fun and could often be used for these movements, but they became dreary and stale after much repetition and, anyway, they often did not convey, simply enough, the ideas we wanted to get across. We began to realize that the terms we were using came to life most effectively when 1. set to a catchy tune, 2. associated with individuals or events and, most importantly 3. used in a group situation with a healthy quota of adults to keep it going and 4. a lively accompaniment on the piano and accordeon. An early, successful, action song, which we used initially for a hearing impaired child, was "Jason can touch his head, Jason can touch his head, Jason can touch his head, and so can I" - set to a gay little tune and repeated, of course, endlessly with different body parts and different children's names. It was good, but we couldn't stick to that forever. Then there was "Jack in the box is a funny wee man, he sits in his house as still as he can, he sits in his house as still as he can, then suddenly out he pops! In out, in out, funny wee Jack in the box, in, out, in, out, funny wee Jack in the box." Then, again, there was the sea song with the chorus "We're going this way, that way, forwards and backwards over the Irish Sea".

There had been also, of course, the inevitable "Head and shoulders, knees and toes", sung to "There is a tavern in the town" which is lively enough, but much too fast for actions, and hopelessly dreary if slowed down to the children's action speeds. We needed new ideas. So, we hit on another plan and progressed to touching body parts in rhythm to lively Scottish music. We could then extend each activity as long as we liked, and did not move on until everyone had completed the action correctly for a few times. It was a way of beating time to the music anyway and no one minded waiting. Finally, we learned the secret of changing the tempo of traditional singing games to enable the children to fit their actions to the music. This was not a question of slowing down a familiar tune, but of giving it a new rhythm and a new beat, distinctive in its own right. This technique was hugely successful with "Here we go Looby Loo, here we go Looby Light; here we go Looby Loo upon a Saturday night. Put your right hand in, put your right hand out, shake it a little a little, and turn yourself about." When you give a children's rhyme a boogie rhythm, you'd be surprised at the result!

While this was going on in our music sessions, things were developing in the gym. Here we had more room to move. We could experiment with different formations - with adults or without, finding our own space, being in a wide circle or a

small circle, a puffer train line or a "promenade parade" round the room. There were endless possibilities. Fortunately, we have found it relatively easy to flood in staff, volunteers, local school children on community projects, and students on placement, not to mention the unsuspecting passer-by, who lingered too long and too curiously in the passing. We have aimed to have as far as is possible a one-to-one ratio. Close body contact for learning new movements was invaluable - the adult guidance being discreetly withdrawn as the children discovered a movement for themselves. But there was another area of body contact which was not withdrawn; the closeness which was an end in itself. It was our Veronica Sherborne sessions which helped so much in giving the children confidence in themselves and trust in a close adult relationship. Here each child, cradled in his partner's lap would experience movement through the adult, swaying and stretching, and discovering his body's capabilities. These soothing, quieting movements to the tune of "Bridge over Troubled Waters" were undoubtedly rewarding, and provided the balance for the more lively activities which preceded them or followed after.

Our "forwards and backward" theme took on new meaning when set to Mike Oldfield's "Blue Peter" or Scott Joplin's "The Entertainer". The movement involved the children coming forward from the back of the room until a tambourine beat indicated change and the word "backwards" directed retreat. This switch of movement demanded quite complicated thought processes on the children's part but, incredibly, they rose to the occasion and relished the experience of a dance sequence in which they made the decisions and they were in control. Inevitably, of course, their concentration flagged after a few directional changes, and only the deft movements of nearby adults would keep the group going the same way. I hasten to add, we are improving all the time!

In all these activities the reward was found in the doing. However, an additional bonus came towards the end of a learning sequence when all the components could be put together to form a social dance. This would be set to the rousing beat of traditional fiddle music. It was possible to use familiar Scottish country dances for this purpose, which could, and often are, with minimal modifications, shared with other boys and girls of the "big" school, as we call it. This sharing, at school disco times, or dance sessions in the gym, contributes to the family feeling of the whole school.

We do, of course, use gross movement in an explorative way too, when we meet the many challenges of gym equipment on another day - beams, bars, slides, ladders, ropes, jumping mattresses, and a whole soft environment area provide interest in themselves, build up confidence, and lead on to the greater challenges of our outside adventure pathway and the fast developing opportunities of both the big school and Muirburn gardens.

There are other forms of movement too, however, and these find expression in the many exciting activities of daily life within the Muirburn family: and here I pass on to the background and functioning of the Muirburn Unit in general.

Over the past ten years, Muirburn has evolved from a traditional slow learning unit to a center for young blind children with multiple handicaps. I use the word "evolved" advisedly because, in 1973, no one would have thought it possible to provide for the needs of so mixed a bag as we have now; but, by virtue of the following, we managed to do it:

1. Careful staff selection - both teaching and house staff are highly and appropriately trained in their areas of work, with the exception of two housemothers who, by dint of experience, have proved their worth.
2. Some inevitable alterations to the physical environment of house and garden.
3. The enthusiasm of existing staff.
4. The pressure of parents, doctors, social workers and psychologists.

5. The growing interest of professionals whose help we wanted and who wanted contacts with us - physiotherapists, the Lothian Hearing Impairment Service, Speech Therapists and so on (we do, of course, benefit anyway from the main school music, gym and swimming staff).

We have also been very grateful for the cooperation of the Scottish regions, who agreed to provide regular weekend transport for their local children. In our unit, we have only two - from the far north and west of Scotland who go home fortnightly; otherwise they are all home by Friday evening and may return on Monday morning - some come on Sunday night. These arrangements, of course, were made for the whole school, and from them we have benefited.

It should be said here that the school as a whole was undergoing change on a fairly radical scale at the time, and Muirburn found itself in a favorable climate for growth and expansion. Recently, two further encouraging developments on a national scale have impinged on our work: firstly, the New Education Act (Scotland) of 1981 (England and Wales have their own) is presently being implemented. It requires individual programs for special needs and the recording of these needs by a multi-disciplinary team. We feel we are now in a position to share this challenge and have already contributed to the first Record of Need asked for by the parents of one of our children. The second development is the knowledge that we are now regarded as the Resource Center for Scotland in the field of multiple handicaps in blind children.

At Muirburn, we have a happy and united team of house and school staff, eager parents, big brotherly links with the young people of the main blind school of which, of course, we are a part. (The seniors, by the way, have two shared programs going with local secondary schools); and we have the valued cooperation and support of the specialists who so gladly come along to share our common aims and "muck in" with the rest of us to provide what, underneath the apparent chaos, is a carefully thoughtout plan of campaign. I should add, most forcibly, that parents constitute an integral part of the unit. They are welcome at all times, either in person or on the phone. They share with us, and the school's parent counsellor, their problems and joys as we share ours with them and, between us, we manage to sort things out to our mutual satisfaction. The five day week provides excellent relief for parents under stress; and, for the parents of local day children, we can always pop the children into a bed for a night or two with their little friends to let Mum and Dad get away together. The children take it in their stride and the parents do eventually come to believe that their children can cope away from home for a short time. Every child has to make a break at some point, whether he is able bodied or handicapped, and we feel that, for ours, the experience is a relatively painless one because they are staying in a familiar environment and with people they already know and trust.

An enthusiastic Edinburgh psychologist, along with our parent counsellor, had prodded us into providing, over and above our usual parent get-togethers, regular three weekly meetings with the parents of our day children. This group of families constitutes problems unique to their situation - where the children's manipulation of their parents at mealtimes, toilet times and bedtime seems to last a lot longer than that of the resident pupils. We can discuss these matters in a happy, humorous and relaxed atmosphere, knowing that we share a common bond of love for these, so often, mischievous little people. These informal exchanges have always been worthwhile and enjoyable for everyone.

I mustn't forget our ladies who help in the kitchen and about the house - they, too, are very much a part of the family, adapting to suddenly changed roles in emergencies, by offering another pair of hands at toilet time, shoe time or mealtimes or comforting some distressed morsel of humanity. We are all in together, sharing the good and the bad times - we and the animals and the birds and the

flowers which make up life in Muirburn Lodge!

I haven't mentioned the daily programs which follows a regular routine from dressing time in the morning, going to school (across the garden) till bedtime. The actual pattern of the day is rigid and relentless (because the children need it that way) but, within it there is much freedom and opportunity for decision making, experiment and exploration.

May I say, finally, that for the Muirburn children, their classroom is the garden, the house, the hills, the sea, the shops and the neighborhood, all of which we have near at hand and lastly, of course, the classroom, where it all comes together and where we sort our collections of cones and conkers, shells and seaweed and where we perpetuate the touch and smells of woods, hills and seaside.

It is all great fun and we love it.

THE DEVELOPMENT OF REACHING IN BLIND CHILDREN

Ann Bigelow
(Canada)

Children born blind are developmentally at risk in a number of areas. However, one of their most obvious areas of developmental delay is in the development of reaching. While this delay is in a motor skill, it is most probable that it is a function of delays in cognitive abilities which in turn are a function of the children's lack of visual input. That is, blind children may not know that objects exist out there to reach for, that these objects have a permanence of their own which is independent of self, and that they can use their own bodies to obtain and explore these objects. The sensory information available to blind children, particularly auditory information, may not provide them with adequate cues for the construction of external reality, i.e., to hear something may not initially cue blind children to the existence of something and/or its location in space. Reaching in sighted infants is initially stimulated by vision yet the development of reaching in blind infants may be more closely tied to their conceptual development, particularly their development of object permanence, i.e., that things are there in a particular location in space even if they are not seen. The sequence of blind children's acquisition of reaching and search strategies may be revealing with respect to the development of object permanence in the absence of vision and the children's use of the sensory information available to them.

A three year longitudinal study was conducted on the reaching and search abilities of five children born totally blind without other handicaps. Ten tasks designed to determine the relative importance of sound and touch in eliciting a reach were presented to the children at monthly intervals in their own homes. Their responses to the tasks were videotaped and scored by two independent scorers for criterion reaching (direct reach and contact with the object) as well as pre-criterion responses (e.g., swiping movements, reaching to area of past contact). The five children entered the study at different ages and participated for different lengths of time. Their ages ranged from 9 to 32 months when they entered the study and they participated in the study from 5 to 25 months. As can be seen in Table 1, subjects 2 and 3 were able to perform at criterion in many of the tasks on their first session and subjects 4 and 5 did not participate in the study long enough to master all the tasks. Nevertheless, the children's collective performance suggests that there was a sequence to the tasks' mastery which is revealing with respect to the growth of object awareness without vision.

Table 1 lists the tasks in sequence of their mastery. Although this sequence is interesting in a number of respects, the discussion will focus around two questions. The first is what do the data indicate about the relative importance of sound and touch in eliciting a reach. When there are analogous tasks using sound and touch alone, the touch tasks are easier. For example, the children responded to continuous touch as in Task 1 before they responded to continuous sound as in Task 3, i.e., they reached for silent toys touching their bodies before they reached for sounding toys which were held directly in front of them. The children reached to cues of previous touch as in Task 8 before they reached to cues of previous sound as in Task 10, i.e., they reached out for silent toys which they had just previously held but were pulled away from them before they reached for toys they had just previously heard but were now silent.

When touch and sound cues were in conflict, the children initially responded to touch cues and only later relied on sound cues. For example, in Task 9 the children had a sounding object pulled away from them at midline front and heard it move to one side. Initially the children responded to this task by reaching for the object at midline front where they had lost contact with it and only

on later trials did they reach for the object in the position where they currently heard it sounding. Therefore, even after the children began to respond to sound cues, on difficult tasks they resorted to previous strategies based on touch cues. Thus it is touch rather than sound which initially cues blind children to an object's existence and/or location in space.

The second question of interest with respect to the sequence of task mastery is what do the data indicate about the development of object permanence in blind children. As you may know, Piaget (1954) indicated that one of the major cognitive tasks in infancy is the development of object permanence, i.e., initially infants believe that the existence of objects or people depends on their perceptions of them. Infants must learn that objects have a permanence and an autonomy which is independent of their own observations of the objects. There are a series of tasks originally designed by Piaget and since standardized by others (Miller, Cohen, and Hill, 1970; Uzgiris and Hunt, 1975), which demonstrates that children develop the concept of object permanence through a series of six stages. These standard object permanence tasks rely totally on visual items. However, there are two ways of comparing the present tasks to the standard object permanence tasks: (1) examine the underlying cognitive abilities which the standard tasks demonstrate and match them to similar underlying abilities which the present tasks demonstrate, and (2) look at the performance of sighted children whose level of object permanence is known on task similar to the present tasks. Utilizing both approaches, the blind children's order of task master suggests that the tasks tap the development of object permanence from Stage 3 through Stage 4 and into Stage 5. For example, Piaget observed that children in Stage 3 of object permanence reached for objects they could not see but were touching their bodies. This is essentially Task 1. Thus Task 1 could be interpreted as a Stage 3 task. Previous work with sighted infants (Bigelow, 1983; Freedman, Fox-Kolenda, Magileth and Miller, 1969; Uzgiris and Benson, 1980) indicates that they do not search for hidden objects on sound cues alone until Stage 4. Tasks 3, 6, and 7 in the present study involve the search for objects on sound cues alone. Thus these tasks may be analogous to Stage 4 tasks. Previous work (Bigelow, 1983; Uzgiris and Benson, 1980) also indicates that most sighted infants must be at least in Stage 5 before they can locate a sounding object which they lose sight of in one location and hear moved to another location. This is analogous to the situation for blind children in Task 9 where they lose contact with a sounding toy in one location and hear it moved to a second location. Thus Task 9 may be interpreted as a Stage 5 task. Therefore, both blind and sighted children may develop object permanence through a cognitively similar process, i.e., the sequence with which they understand the concept of object may be parallel although the senses used to organize information are necessarily different.

This conclusion is not meant to imply that blind children, who begin to reach for objects on sound cues alone know the same thing about objects and environment as sighted children who begin to reach for objects on sound cues alone. Sighted children see objects and have been reaching on visual cues for many months. Obviously children learn a great deal from seeing and manipulating objects. It is probable that blindness does effect children's understanding of objects, space, and the environment in general for a good many years. It is reasonable to assume that subtle differences in reality exist throughout the lifespan of a person who has never seen compared to sighted individuals. Nevertheless, it is in the early years that the critical constructions to reality must occur in order for the individual to function independently. Hence, it is in infancy that blind children are most vulnerable to developmental risk. Much of the information babies use to learn about themselves and the environment comes to them through the visual system. Some theorists have suggested that the visual system is the critical sense modality in infancy because it is the most important in the acquisition of knowledge. Children

born blind must construct reality without this critical sensory information. That most do is an indication of the flexibility of the early cognitive structures. That they do so in a manner which parallels the process in sighted children is an indication of the universality of our underlying cognitive organization.

This paper was presented at the Second International Symposium on Visually Handicapped Infants and Young Children, Aruba, 1983. The research was aided by Social and Behavioral Sciences Research Grant No. 12-20 from the March of Dimes Birth Defects Foundation, by the St. Francis Xavier University Research Council, and by the St. Francis Xavier University Research Council, and by an equipment loan from the Nova Scotia Department of Social Services.

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Table 1

Sequence of Mastery of the Reaching Tasks and the Criterion Sessions for the Tasks for each of the Blind Children

Tasks	Subjects				
	1	2	3	4 ^a	5 ^a
1. The child locates a toy which is touching his/her body. It matters little whether this toy is sounding or silent.	2	1	1	2	2
2. The child locates a sounding toy which is pulled away from him/her at midline and remains sounding in front of the child where it was pulled away.	3	1	1	4	
3. The child locates a toy which is sounded directly in front of him/her either at midline front or midline right or left.	3	1	1	5	
4. The child locates a sounding toy which is moving in a horizontal arc around his/her head.	3	1	1		
5. The child locates a toy which he/she has dropped. It matters little if the dropped toy is sounding or silent.	4	1	1	4	
6. The child locates a sounding toy which is sounding from under a cover, i.e., the child uncovers the toy and obtains it.	5	4	1		
7. The child locates a toy which is sounding in a position higher or lower than midline.	5	5	1		
8. The child locates a silent toy which is pulled away from him/her at midline and remains in front of the child where it was pulled away.	8	5	4		
9. The child locates a sounding toy which is pulled away from him/her at midline and is moved to one side where it remains stationary. The toy is sounding throughout the procedure.	10	8	3		
10. The child locates an intermittently sounding toy which is moved in a horizontal arc around the child's head. The successful reach occurs when the sound is off.	12	9	4		

^aSubjects 4 and 5 left the study before they mastered all of the tasks.

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(U.S.A.)

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THE MOST PERSISTENT LIE ON EARTH:

"A HEALTHY MIND IN A HEALTHY BODY"

Henk De Beijer
(The Netherlands)

Introduction:

Some of the statements that I am going to make may come as a shock to you. Yet, I believe it is high time that we pull our heads up out of the sand and go in for some hard thinking about the basic human values involved in the work we are all so deeply engaged in, that we tend to forget that the practical techniques do not fall out of the blue sky but are, or rather, should be, the off-spring of basic ethical norms, which we have kept up to now at a safe distance, because reflecting upon them may entail a nasty self-accusation. It is in no way my intention to pronounce any judgement about any individual person or case. If anyone should feel offended, because a particular statement seems to refer directly or indirectly to him or her, let it be perfectly clear to them, that if we condemn theft, that never can contain any judgement on a particular thief. This same point of view is fully applicable to all abstractions or generalized ethical norms. The abstraction of generalization is necessary to show the consequences involved, but they never contain any judgement of an individual's infringement of a norm.

Rejection of the "Unfit"

I'm absolutely sure that all the blind participants in this conference at one time or another have been confronted with such consoling remarks from sighted strangers or even acquaintances, as: "If a thing like that happened to me, I'd kill myself!" My own first reaction in such a case usually is to offer this sort of compassionate people a rope and tell them to go hang themselves on the spot. But I also usually manage to restrain my anger, feeling more sorry for them, than they do for me. This reaction to the confrontation with a blind person has nothing to do with lack of education. Quite often it comes from very well educated people and in my own case, I once met an ophthalmologist who expressed the same thing in a generalized way, saying he'd take his own life if he should ever become an "invalid", as he put it. The simple truth is that these people are absolutely sincere in what they say. For them, blindness makes a man so inferior that life isn't worth living any more. The rejection of blindness is the rejection of inferiority, seemingly in accordance with Charles Darwin's theory of natural selection, resulting in the rejection of the "unfit" and the "survival of the fittest".

I feel sorry for these people. I feel sorry for all those who are incapable of appreciating the human value in a human personality, a human individuality which does not and cannot depend upon a body with all its defects and imperfections, but which depends upon the human mind, upon reflective consciousness.

A New Era

Two years ago, we, quote unquote: celebrated the International Year of Disabled Persons about which I, for one, had very strong doubts long before it started. Those doubts were not taken away during that year. On the contrary. Not even after it. It may sound rather sarcastic, but in a way, I have the

impression that the IYDP -- as it is called euphemistically, as I see it -- ushered in a new era: the era in which to do away with the handicapped! Personally, I did not hear a single voice that ventured to emphasize the value for human society of the mere existence of "disabled persons".

A very intelligent, severely handicapped young woman -- if this were a newspaper report it would probably read: "a severely handicapped but notwithstanding that very intelligent young woman" -- once said: "If I had been born in....." I'll use a fictitious name because you never know if somebody might not be offended if I mentioned the place she referred to, "If I had been born in Monte-Preto my parents would very probably have thrown me before the wolves," she said and she added, "I am extremely happy I was not born in Monte-Preto!"

It may come as a shock to you, but is it really so strange that these backward people react in such a way? Are we, in the more developed world, so much better than they are? All right, we don't throw little babies before the wolves, because they are born with a handicap. We have developed far more humane methods . . . to get rid of them. If we suspect that a child may be born with a serious handicap, we decide to have an abortion. And our modern doctors are quite capable of finding out before birth whether there is a good chance of a baby being born with a handicap. In all modern hospitals, except for some adhering to religious principles, amniotic fluid examination is a daily practice, enabling us to ascertain in an early stage if there is anything seriously wrong with the foetus. I know I am going to get strong reactions to what I'm going to add now. I will be accused of emotional rhetoric and my arguments will be rejected on personal grounds, of the same kind as the ones I was faced with when I articulated these thoughts for the first time. Nevertheless, I'm going to pronounce them again, with a strong underlying hope that I may shock you into a discussion of the basic values involved in our work. I ask you: is there really so much difference between throwing a new-born baby before the wolves and having it aborted? The reasoning applied to authorize the act of getting rid of it either before or after is the same, whether we like to hear it or not. It is the purely logical consequence of our ethical valuation of a life worth living or not!

Though it may sound as emotional rhetoric, I want to repeat the last words of that severely handicapped young woman I just referred to and who said, "I'm extremely happy I was not born in Monte-Preto." Nowadays, many a handicapped person might spell out that same remark in a different way: "I'm extremely happy I was not conceived by liberal parents!" Let's come to our senses, ladies and gentlemen! Let us implore all medical professionals all over the world to re-evaluate their ethics because this means nothing less than the denial of human value to a human being on the ground of a defective physique. What's the difference between the killing of psychiatric patients during the Nazi regime in Germany as inferior beings and the denial of life to a defective foetus or the killing of a defective new-born baby? There is no fundamental difference, if submitted to the laws of logic.

Modern medicine, and not only modern medicine, has embarked upon a very dangerous path for humanity as a whole. Our doctors get an almost purely technical education. There is no longer -- if there ever was -- a holistic view of the human being; the human being is treated as a bio-chemical machine and as a consequence, the difference between life and death is nothing more than that of a physical function and malfunction. I repeat: this attitude towards human life contains no impediment whatsoever against ending a life seen as defective and therefore as inferior. Because, if human value depends upon physical perfection, a physical defect is equal to inferiority. Consequently -- and logically, of course -- it's only one small step from the decision to terminate a pregnancy because of suspected defects to terminating the life of a new-born baby for the same reason, which, whether we believe it or not and whether we like it or not, happens a lot more than we all know. And I'm not referring, as far

as this is concerned, to the so-called passive euthanasia practices in which medical intervention is withheld from a baby that has no chance to live without it.

Anyway, from a logical point of view, there is only a difference in barrier height between the two acts; the second is one step up the same ladder as the first one; and the next purely logical step up is to liquidate adults afflicted with the same defects; and from there on, all others who are considered to be inferior.

Hitler was a madman! Of course he was! But he didn't commit any infringement of the rules of logic. From his vantage point, all his acts were purely rational.

Am I taking my arguments too far? Were those few voices in the 1930's taking their arguments too far when they warned about Hitler and were not believed? All right, you may say, but our medical professionals are proving beyond doubt their high ethical approach towards human life in their often incredible efforts to save even unsavable life! And aren't our surgeons doing anything they can to offer life to a new-born baby, born, for instance, without an esophagus (that's a gullet) even if, besides that, it is very mentally retarded and has other handicaps as well? Aren't they even going to such lengths as to deprive uncooperative parents of parental control over such a baby, for the sake of saving the baby's life? The question is: are they really doing it for the sake of saving the child's life? Is an artificial heart implant at this present time a life saving operation or . . . or what? Am I being too suspicious if I raise the doubtful thought that many of these pseudo heroic medical struggles are not really being fought for the sake of the patient but for the success and fame of the surgeons? Modern medicine, as I said before, has become a highly technical profession for which, in many cases, not the patient but the feat achieved on the patient seems to have become the final goal.

Human Value

I am not accusing our doctors of being potential assassins. I'm accusing them -- though certainly not all of them -- of holding a false view of the fundamental value of human life, which, on the one hand, they pretend to protect, even to the extreme point of absurdity at times, and which, on the other hand, they are unable to recognize in its only true, fundamental value, of human consciousness. However, instead of accusing anyone at all, we had better examine our own consciences and ask ourselves whether we are so much better than those whom we accuse. How many of us, so deeply involved in our services for visually handicapped infants, that we even dedicate very costly international symposiums to them, would decide not to have or not to advise an abortion, if we would know in advance that a baby was going to be born blind? I bet most of us, including myself, would have a damned hard time taking that decision. Let's not have any illusions about ourselves. Let's confess quite honestly that if we knew in advance that a baby of ours was going to be born blind, many of us too would decide for having that abortion.

And yet, the fundamental motivation behind the work we are all engaged in up to our necks is a struggle against that false view of human value, against the attitude that approaches other people as inferior beings because there is something about them that distinguishes them from what is considered to be normal. A pretty girl, winning a beauty contest, is really being posed as an example of what all girls should be like and consequently, those not reaching such standards are inferior. That is the basic incentive in all contests: proving superiority over inferiority.

Poor beauty queens! Poor people with healthy bodies! How terribly poor are all those whose minds are not capable of rising above that sort of super-

ficial, trivial and even banal level! and, "mutatis mutandis", blessed all those who, because of the hard blows they were compelled to suffer in their lives, were able to develop great strength of mind, of spirit and of consciousness -- the latter of which includes the previous two. And blessed all those who "a priori" had the mental inclination in their characters to join the ranks of the so-called lesser brother because they -- and I hope all of you are amongst them -- have realized, perhaps only subconsciously, that it is essential for the progress of mankind to wage a constant war on the devaluating attitudes towards human life, because for every human being who recognizes his own intrinsic value -- which does definitely not depend upon a healthy and perfect body -- there is no better cause in life than to fight the destructive forces of the attitudes that degrade human value to nothing more than physical well-being.

Evolution

According to the famous French existentialist philosopher, Jean Paul Sartre, in his extremely clever, but at the same time extremely awesome, treatise, "l'Être et le néant" the human mind is a "maladie d'être -- a sickness of the being and therefore an absurdity. Evolution, according to this way of thinking, has led to an absurd product: the human mind, which should never have come into existence. As a consequence, every deviation in this loathsome absurdity is even more absurd and therefore more loathsome. Fortunately, Monsieur Sartre did not live up to his own loathing because he became a very much involved man. Why, I ask you, and I think I can give you the answer, though deep down in our hearts we may also find the answer absurd. Nevertheless, I think that we are the answer, that is, the blind, the visually handicapped, the visually handicapped infants and young children we are all so involved in and all of us, who one way or another, have a cross to bear through life.

"I'm afraid," said the hospital chaplain with whom, at the time that I lost my sight eleven years ago, I had long discussions on the magnificent vision on the evolution of mankind of another Frenchman, Pierre Teilhard de Chardin, "I'm afraid," he said, "Teilhard leaves no room for suffering." He was more confused than I was about what was happening to me. There was no pride involved on my part and certainly no religion as an opiate. There wasn't really any religious conviction involved at all -- though I admit that I am a deeply religious man, but at the same time deny that that was the cause of my acceptance of my fate, because I reject that kind of religious arrogance and refuse to see God as the boss of a puppet show. My reply to the chaplain was no more than the residue of moments of experience. "You're wrong," I said. "Never before in my life have I experienced such wonderful moments of penetrating into other people's minds and others into mine."

The evolution of life is an unimaginable cosmic game of chances following a path of complication, or complexification, of matter which results in ever increasing levels of consciousness. About one million years ago, a threshold was passed, as revolutionary as the threshold of the genesis of life itself: consciousness became reflective; it became conscious of itself; man was born. From that moment on the process of complication became more and more a willful process of socialization and collectivization, not resulting in, as so many fear, loss of personality, but in an increase of personalization and individualization, which go hand in hand because true socialization and collectivization are a process of inter-subjectivity and inter-subjectivity depends upon personal involvement and personal involvement depends upon personality and individual freedom of choice. What brings about more personal involvement than the seemingly unlucky chances? Would I be standing here before you if my chances had been otherwise than they were? Would I be doing the job I'm doing, without being paid for it, if I had not lost my sight and received my Dutch disability insurance? Would I

be as deeply involved in this community if I had not married the woman I married? Would I have the most fascinating international friends, acquaintances and relations if my fate had been otherwise? Is it a surprise to you, if I dare to say, that I love my fate?

If we cast only a cursory glance back at history, it should be perfectly clear that all innovative movements sprang forth from very small groups of people, from individuals at times, from the private initiative of a handful of involved individuals who decided to fight the tremendously strong conservative forces of what is known in German as "Gesundes Volksempfinden", i.e., the so-called sound common sense of the masses of the people which is actually, really packed full of prejudice against all that is not deemed to be normal. And the worst substitute that I have ever heard of the word "integration" was the word "normalization". God forbid that we should all be "normalized". Progress would instantly come to a standstill. It is not the shapeless masses, not the mainstream, that produce the winds of change; they are the consolidation of previous winds and even storms at times.

You may accuse me of being elitist and I'll plead guilty, on one condition, that it be recognized that the elite I'm referring to does not consist of power groups, nor of an aristocracy, not even of militant action groups, but of handicapped people; of handicapped infants and even babies; of their parents, their educators, their counsellors and all those who deliver services to them. And the strongest of them are we, the blind, in more than one sense: in the sense of being the best organized group, both internally -- among themselves -- and externally, as far as the agencies for them are concerned. And in the sense of being the group that has the strongest impact, especially emotionally speaking, upon the world around them and therefore act as a strong catalyst for involvement, often, in the initial phase, sentimental involvement which in most cases may very quickly be moulded into conscious, inter-subjective involvement, many times as a consequence of personal setbacks in life, be it of a relational or of a physical or mental nature.

We all know to what great heights the human mind may rise, not in spite of but precisely compelled by, physical limitations or so-called anomalies. Therefore, I proclaim that the greatest and most persistent lie on earth since the times of the Roman Empire is contained in the proverb of those times: "mens sana, in corpore sano" -- a healthy mind in a healthy body. All of us present here are proof that it is a lie!

EARLY INTERACTION BETWEEN INFANTS BORN BLIND AND THEIR PARENTS

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The subject I am going to talk about are thoughts about the development of the blind child as an attempt to find causes of inappropriate socio-emotional development in the blind child. These thoughts have arisen in connection with my colleagues and my own work with observing, training and treating blind infants and their parents in Denmark. The basis of these thoughts are apart from the practical experiences received from our daily work, partly from knowledge I have gained from Selma Fraiberg and Dorothy Burlingham's many articles and on the research of affect and language development carried out by Daniel Stern, Berry Brazelton and others, which contribute to illustrate how human attachment is established in early infancy.

Observation of blind children in Denmark tells us that the child can be caught in many traps during development from newborn infant to blind adult and these can cause emotional disturbances in the individual person. The disturbances might be behaviour patterns covering intermediate inappropriate ways of behaving which can be eliminated through an intensive determined treatment for a short period to very serious psychotic disorders. All blind children do not develop such serious disorders in their personalities as the last mentioned, but I believe that all blind children are in danger of developing that kind of severely inappropriate socio-emotional disorders.

The disorders are specially obvious when the child is 2 - 3 years old. At that age the deviations in the areas of motor, language and social development between a seeing and a blind child is clearly observable in the behaviour of the infants. The inappropriate development, however, can be sensed earlier in some children giving the suspicion that it starts at an earlier stage of life. We found that a deviation in development seemed to be observable in the behaviour of several blind infants when they were 6 - 7 months old. At this age an important difference between the behaviour of the blind and the seeing child can be pointed out in the degree of activity and interest they show in the world around them. The seeing infant tends to be more awake during day-time than at earlier age and as a consequence he is more active in getting hold of toys in order to examine them. Furthermore the seeing infant seems to be more curious and shows wishes to explore his surroundings, and slowly by help of experiences he is being aware that a world exists outside his own bodily self. Likewise there is a growing sensation about his ability by own acts to influence the state of other minds. Generally speaking the blind infant at the same age seems to be more passive lacking the wish to examine the surroundings. The awareness of other people and their minds existing separated from the infant seems vague, and the symbiotic phase seems prolonged. Thus the awareness of being able to influence other people's state of mind by means of own acts is not yet sensed by the blind infant.

Is it possible to find the causes for these developmental differences appearing when the infants are 6 - 7 months old? I think the main reason can be found in the blind child's handicap as I will describe in the following. Seen from a biological point of view to be born without the visual sense is wrong and abnormal. It can be discussed which sense is the most important one, but I believe that the visual sense is the most important in the first years of life because it is an important means in the process of establishing human attachment. In order to understand what the loss of the visual sense means it is necessary to know how this sense is used by seeing infants. Biologically the visual sense is meant to cooperate with the other senses. An important intersensory coopera-

tion between the visual sense and the other senses is lost for the blind. Furthermore the vision is used to get information about things we cannot actually get into physical contact with, i.e. things out of reach, big and dangerous things, etc. The visual sense is also used by the infant to build up a world of experiences and concepts as objects are sorted out, organised and categorized among other things by help of vision. The infants' imitation in using objects and acting like others is also mainly made by the aid of vision. Furthermore the visual sense is very important as a motivating factor for the infant. Visual stimulation intensifies the child's curiosity, and it helps the child to understand that an exciting world exists outside the child's bodily self. It should also be mentioned that vision is a very important steering element of the interaction going on between infant and mother and later on between the child and other persons, e.g. friends, etc. Thus the visual sense is of utmost importance for communication with other people.

As we all understand the visual sense cannot be substituted by another sense even if we often try to use the tactile or the auditive sense as a substitute. Therefore we must use all our knowledge and imagination about the other senses in order to compensate for the loss of visual sense to help the blind child get a basis of experiences and a development making him fit to live in the world of seeing people. But no matter how hard we try this can never replace vision. E.g., how do we replace the joy the seeing infant feels when he realises that he can control and master sensory impressions when he wants to himself? Lying in the cradle, alone and awake, the seeing infant can decide that he wants visual stimulation. He can open his eyes, look at an object etc. inside the limits of his visual field and he can stop looking at the object and return to it whenever he wants. This can be seen as a kind of an active act of will essential for the infant to experience. The blind infant cannot to the same extent by help of his other senses get the same feeling of being able to master and control his sensory stimulation.

This summing up shows the most important functions of vision and gives an impression of how difficult it must be to start life without this important sense. However, there is one stage of the development of the blind infant where I regard the loss of vision as being extremely critical. This is in the first year of life when establishment of human attachment is taking place. To understand this it is necessary once again to look at the seeing child. We know that the normal newborn infant is able to use all of his senses from the first day of life and is able to combine the perceptions into experiences. We also know that the infant is interested in being stimulated and that the infant rapidly learns to make use of sensory experiences building up a still growing world of knowledge. This counts for social contact as well. The child is born without cognitive awareness of the existence of other people. This knowledge and awareness is established by help of experiences. In the first stage of life the sensations the child is specially sensitive to is his own internal state. When the infant feels uncomfortable, he cries and he soon finds out that somebody does something to change this feeling and make him feel comfortable again. In this connection the infant receives visual, auditive, tactile, taste and smell stimuli from the mother. All these sensory perceptions are unified by the infant and in a very short time they become synonymous to mother, and mother is related to feeling of pleasure. It is important to stress that the infant does not passively build up the ability of distinguishing between mother and unknown persons via his senses - the child interacts actively in many situations with the mother during the day, and it is mostly on basis of this interaction that the infant establishes human attachment.

In the earlier literature the reactions of mother and infant were described as if they reacted independently. This resulted in a list of mother and infant reactions, but each was regarded as reacting alone, separated from each

other and not as part of an interaction where every act is influenced by the reactions of the other part in the interactions. Recently the view has been that mother and infant are two individuals having a dialogue like a verbal dialogue, but without words. The dialogue takes place on basis of small signals which the mother and infant together have given special meaning. In this manner they are able to communicate with each other. An example of how a communication or dialogue between mother and infant is established will be given: As mentioned before the infant is able to use all of his senses from the first day of life, but he has no acquired reactions. The infant is not able to formulate his needs, but by crying he can signal discomfort. Most mothers react to the crying and through a kind of trial and error the mother satisfies the needs of the infant. An understanding arises in the child that it is possible to have discomfort eliminated if he cries, etc. In the beginning the infant often takes the initiative of starting an interaction with the mother, while the content of the interaction is mostly steered by the mother. All children are born with a desire to be actively stimulated, but they also want to be able to control this stimulation process. If this need is not fulfilled - if the child does not get rewarded when he acts, then he has difficulties in establishing a sensation of his abilities to influence, master and control his own acts as well as those of the surroundings. In this case the infant is in danger of gradually becoming more and more passive and despairing. If the persons around the infant do not react to the infant's signals and the infant is not rewarded when he calls for attention and therefore experiences no social success, the infant is likely to turn his attention to activities he himself can control. One of the nearest and easiest to turn to is perceptions from his own body. By moving the infant can decide to start and stop a sensory perception. The consequence might be that the infant rejects social offers and starts being more and more absorbed in perceptions from his own body. This behaviour can be observed in deprived infants, but also in blind infants. This is an inappropriate behavior we do not like because it can have serious consequences for the socio-emotional development. It is therefore essential to the infants to perceive that being active, curious and social interacting is a rewarded behaviour. It pays to do things.

Before making a comparison between the differences in the process of establishing attachment in a seeing and a blind infant it is necessary to describe some important factors in the interaction between mother and infant. Research made by Daniel Stern and others has shown that it is not unimportant how the interaction between mother and infant is taking place and especially it is important to stress that there is a limit to how much sensory stimulations the infant can manage at a given moment. If this limit is passed, the child becomes uneasy and actively rejects further stimulation. Too much stimulation clearly has a negative effect. It also has been observed that infants use signals to show when they want stimulation from the mother started and stopped. One of the most common signals seeing infants make use of is to look at the mother when he wants stimulation and to stop looking when he wants the stimulation to be stopped. If the mother does not see that signal and continues the activity the infant starts to show motor uneasiness, starts yawning and ends up crying. When the infant is calmed and wants the activity to start again he looks at the mother again. Many research observations have shown that the eye contact is the most important tool the infant has making it possible for him to steer interaction with his mother. Other important tools are use of voice, gestures, movements and facial expressions. However, looking at or away from the mother is the most important and delicate signal the infant has to tell when he wants stimulation to be started or stopped. Vocalizations and movements are reinforcing signals for the same - or they simply appear as elements in the interaction going on to which the mother can be attuned. Signals consisting of vocalisations and movements serve as cues to help the mother to match the intensity of her actions to

the infant's.

The blind infant does not have the wealth of visual information the seeing child constantly has when being awake. The loss of visual sense does not only form an obstacle to build an empirical basis as rich and varied as vision provides for, but also form an obstacle to establishing attachment. The visual sense helps the seeing infant to understand the existence of other people. The blind infant cannot in the same way reach this understanding via the information he gets from other senses. Mostly, I think, because it is much more difficult for the blind infant to control the social interaction with the mother as I will describe in the following, because the best way of telling the mother to start and stop interaction is to look at or away from her. We can ask: Are there left any possibilities for a blind infant successfully to tell the mother to start and stop stimulation and by this get the perception that he too is able to influence and control his surroundings? How does the interaction between mother and blind infant go on? Als, Tronick and Brazelton have made video tapes comparing interactions between a blind infant and a seeing infant and their mothers. They observed that the behaviour of the two mothers was very much alike. Both used touching the infant, used movements and vocalisations to attract the infant's attention. But the activities the mother of the blind infant used were more explicit, repetitive and amplified.

Looking at the means the blind infant has to start and stop stimulation interaction with the mother it is understood that this necessarily in many situations has to happen in a different way for the blind infant because he cannot use the gaze as a signal. Can, for example, gestures and movements replace the gaze used as a signal when the blind infant wants to start and stop interaction with the mother? Blind infants as well as seeing infants use movements when interacting and mothers interpret these movements as signs of joy, discomfort, etc. E.g., the seeing infant wriggles away to reject stimulation when the mother has not observed the gaze signal indicating: stop stimulation. These movements are often accompanied and followed by crying. This motor pattern is also seen in blind infants and you cannot be mistaken when the infants via these movements show that they wish a stimulation to be slowed down or stopped. An example of using facial expression as a sign to have stimulation stopped can be a yawn and blind infants often show this behaviour pattern. If we interpret this as a sign of the infant being tired and wanting to sleep there is a danger of misinterpreting this signal. Perhaps the infant just wants a short break in the stimulation? Another motor signal often interpreted as an invitation to interaction is the smile. The selective, social smile behaviour in seeing infants is developed when the infant is about 6 months old. The problem is that we cannot expect the blind infant to have the same selective smile behaviour. Furthermore it is interfering with the well known listening attitude. The quiet, listening, concentrating blind infant who does not give the normal signal saying that he wants to be stimulated is likely to be left alone because normally a mother interprets it as a wish to be left in peace. A more active way of asking for interaction are maybe gestures and movements which we would call stereotype movements or mannerisms when they occur later in the child's life. Are these movements originally a sign from the infant showing a wish to be stimulated? Is it simply movement showing that he is awake and wants attention here and now? A last example of what a blind infant can use as an invitation to interaction is the "reach-out" movement which the blind infant can use to get hold of an object or a person. But this demands that the concept of object constancy is conceived by the blind infant - and this is often developed late in a blind infant.

What about sounds - can the infant use sounds in order to start and stop interaction with the mothers? One of the best ways to call for mother is through crying. All mothers react to that signal and interpret it as a signal from the infant wanting a change in his situation. For the seeing infant in an

interaction situation crying is the last step of the signal-sequence: Looking away from the mother - stiffening - motor uneasiness - rejection - crying, and in many cases the blind infant has to use the last mentioned signal - crying - to make the mother slow down or stop interaction if stimulus is too overwhelming. Cooing can be a good way of inviting to interaction for a seeing as well as for a blind infant, but blind infants often coo less as they listen more. The infant cannot coo and listen simultaneously. As mentioned it is quite easy to misinterpret the behavior of the blind infants and correspondingly it is difficult for the blind infant without the visual sense as help to interpret the signals from the mother correctly. Consequently it is understandable that the mother and the blind infant must experience many interaction situations which are not attuned and as a consequence ends in a conflict. Is this one of the reasons why blind infants easily develop autistic behavior? Is this the reason why blind infants' level of activity seems to slow down when they are 6 - 7 months old - the age when seeing infants become more active and curious and able to steer their own situation? Is it possible that many blind infants tend to give up being active at that age because they have gone through a number of situations they were not able to steer and thus have not the same amount of social success in interaction situations like many seeing infants have achieved at that stage? Furthermore it is well known that mothers of blind infants in the first year often are in a state of depression and this depressive state might have a learning as well as an affective influence on the behaviour of the infants. It should also be added that many blind infants have had a very hard start in life because of a complicated birth, low birth weight, staying in a couveuse, etc. With this in mind I feel it easy to understand why blind infants are at risk to develop socio-emotional disorders in the first years of life which can influence the developmental patterns in the years to come.

I have raised a lot of questions to which I have not given the answers. My intention has not been to give these answers, but more to try to start a discussion about how we in the best way can learn to fulfill the needs of the blind infants. I have stressed that to be born blind is not only a physical, but a big social handicap as well. The amount of knowledge and experiences the blind can get about the world is limited as well as his abilities to control and master his physical as well as his social surroundings. I feel that these difficulties in early infancy are the main reasons why many blind children develop socio-emotional disorders. I do not know how to avoid these disorders. I believe one way is to get more information about how the blind infants establish human attachment. Studies of interactions between blind infants and their mothers is a way to get this knowledge.

Today we know a little about the interaction-patterns between seeing infants and their mothers. Our situation is that we do not know enough about blind infants' interaction with their mothers. It is my hope that we will get to know more about this in the years to come and to gain information about how to steer the socio-emotional development in the blind infant in a healthy direction.

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REHABILITATION EDUCATION OF VISUALLY HANDICAPPED CHILDREN

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A Short Look at the History: Rehabilitation of Visually Handicapped Children

There are roughly 30,000 visually handicapped people in Finland, a country of 4.8 million people. About 180 of them are under seven years old, and about 50% of them are multiply handicapped, either because of mental retardation, deafness, cerebral palsy, or other diseases. There are about 30 visually handicapped children born every year.

The first school for the blind was established in 1865 in Helsinki and soon a second in Kuopio in 1870. Later both of them were closed and in 1972 a new school was founded in Jyväskylä which is supported by the state as well as a small school in Helsinki for Swedish speaking visually handicapped children.

Actually, the first steps to rehabilitate visually handicapped children under seven years of age was when the book, "How to Educate Visually Handicapped Children Before They Reach School Age", was published in 1934. That book was given to the parents of visually handicapped children by the Central Association of the Blind, founded in 1928. The book gave advice on how parents could teach the children to use their other senses and to improve different skills. That book also advised that because of compulsory education, these children should go to the blind school when they reached seven years of age. That book was used until the 1960's.

In 1966 the Central Association of the Blind established a first office for a person who would work in the whole country with the visually handicapped children in a home based and local program. By the 1950's the school for the blind was giving rehabilitation (or so called adjustment courses) to these children and their mothers. After 1966 the courses were organized by the counsellor around the country. In the courses the families were given lectures from the area of rehabilitation, the children were played with, and mothers and children had play hours together.

From 1966 the Central Association of the Blind paid all the expense of the courses until 1972. After that the change in the social legislation made changes in the financing so that the Central Association recieved the expenses from the ministry for Social Affairs. That gave the possibility of having different aids paid through the social legislation, for example all visual aides, even CCTV, tape recorders, brailers, and so on.

A low vision clinic in the Central Association of the Blind was also founded in 1976 and that service is totally free for visually handicapped people.

In 1977 a second office was established for a rehabilitation counsellor for children and the country was divided into two areas. The third office was established in 1983 and now the country is divided in three areas. In 1980, a center based program began with a kindergarten teacher and a child care worker.

How to Find a Visually Handicapped Child and Start Working in a Home Based Program

In Finland the new born children have very good care from the health service. They are examined very early in the hospitals and get a continuous follow up service until school age by local health nurses. If something special occurs the parents usually contact the nurse because she works in close contact with the families. She sends children to a doctor if she finds anything that needs

to be explored more. If the problem is with the eyes the child is sent to an eye clinic. So mostly severe visually handicapped children are already found when they are 2-6 months old. Mildly visually handicapped children are found later when they approach 3-5 years old. Usually ophthalmologists inform families about the service for the children from the Central Association of the Blind. Very often they even send case records about a child to a counsellor and also to a public health nurse so that those people can start to work with the family. Some families themselves contact a rehabilitation counsellor or the Central Association asking if they have some service for young visually handicapped children.

When a counsellor has received a name and case records of a new child, including all those who already are diagnosed multiply handicapped children, she contacts the family asking if she can visit them. Usually that first visit is very important to a family because they can meet a person who listens to them and has some special knowledge about blindness. The counsellor also asks many questions to get a picture of the situation and the discussion might last many hours, because the family will want to know about the different possibilities the child still has. All those questions are discussed. The counsellor also plays with the child and tries to show and advise the family of ways they can exercise with the child. If the counsellor has parents' permission to speak about their problems she visits a public health nurse and social security office informing them about her services and counseling them on how they can help the family. She also tries to find any local people who would be co-operatively minded and work close to that family. For example: physiotherapists and psychologists. The counsellor also informs local ophthalmologists about the services.

Home visits are made as often as possible but usually only up to three times in a year. That is why those local people and services are important. Later those local people are day care workers or kindergarten teachers who work in kindergartens in such a way that a visually handicapped child could be placed in a group with non-handicapped children. That is an important placement for a handicapped child to start becoming integrated.

Those local people don't usually know anything at the beginning about the rehabilitation of blind children so they need a lot of advice and meetings. A rehabilitation counsellor tries to organize situations where those people can come together with parents. Those meetings might be in local hospitals, child health centers or kindergartens.

Center Based Program

The Central Association continues to organize courses for families that were started in 1966. Today these courses are for both parents and handicapped children, but not for other children. Each family can participate once a year in a course. Parents can also bring a local person to a course. This might be a public health nurse, physiotherapist or kindergarten teacher. Usually the local authorities pay the expenses for them. To the families the courses are free; the expenses for them are paid through the social legislation. Courses last five days, from Monday to Friday. From three to eight families are together, depending on the age level, sometimes more. The personnel that works the whole week consists of three local rehabilitation counsellors who already know the families from their own areas. Also involved are two people who work all the time in that center based program. From outside for the week, there are three to five paid child care workers.

There are two courses for children 0-3 years, two for 3-5 years and two for 4-7 year olds. The course for six year olds is organized in the school for the blind in Jyväskylä. That course is in the blind school because compulsory education starts for visually handicapped children when they are six years old.

That first school year consists mostly of different preschool skills. That is why those children can spend that year not only in the blind school but also in a local kindergarten.

The program during the week at the first course is divided into lectures and discussions for the parents. There are consulting hours for the ophthalmologist, pediatrician, and psychologist. The lectures are about child activation, physiotherapy, music therapy, social security, mobility, ADL-skills, low vision aids and so on. At the beginning the courses have a more psychological emphasis and later more instructional. But in all courses parents have a lot of time to have discussions with professionals and also together with other parents.

During the course the family has a consulting hour in a low vision clinic that is also in Central Association and if a child has any useful vision, he can very early get different magnifying glasses, spectacles and binoculars. Some children even get a CCTV when they are six or seven years old. Before they receive those aids they are taught to use them by a low vision teacher who works in that low vision clinic. Through the Invalid Welfare Act the aids are paid for all children.

In the courses the children have their own program, during which they are examined in different skills; in mobility, using low vision, using hands, and ADL-skills.

At the end of a course the parents and rehabilitation counsellor from their own area have a discussion hour together. The parents receive specific information about their child and what they can do from now on as well as what the good skills are that their child already has.

Besides these courses a kindergarten teacher and child care worker also organize individual periods where some parents also bring other children of the family. A family can attend these periods although they have been attending a course. Here the parents can gain more specific knowledge about their child and their skills and they can follow all the time what the professionals are doing and how they are playing with the child. Usually during this period they have close contact with a low vision clinic. These periods are usually 1 - 4 days. Very many local professionals who work with a family of visually handicapped children come to these shorter periods.

Other Supporting Programs - Center Based and/or Home Based

Finland is divided into five districts of University Central Hospitals and within those areas there are 16 central hospitals. All of them have a child clinic. In Helsinki there is also a Children's Hospital that is owned by communes who pay the expenses and provides services. Central hospitals also organize periods to explore and at the same time train a child. It is emphasized that at least one parent stay all the time during clinic periods so that the child feels secure.

Two years ago in Finland's Northwest University Central Hospital a program was started for handicapped children and their parents, where the parents may stay in the unit with the child and follow all examinations that are given to the child. That unit serves all kinds of handicapped children but almost every week they have one visually handicapped child there, too.

That kind of action is an experimentation and that kind of unit is planned to start in some other hospitals.

Childrens' Hospital in Helsinki-Lastenlinna (The Castle of Children)

In that hospital the severely handicapped children might receive periodical rehabilitation. The parents are welcome to participate in the periods but since they can last two months, parents are not able to be present all that time. During these periods physiotherapists, occupational therapists, speech therapists and psychologists try to teach the child some special skills. That hospital has one unit where a concentration of visually handicapped children have their periods.

A Unit for Deaf-Blind Children in School for the Blind, Jyväskylä

In 1981 a deaf-blind unit was founded which started a concentrated program for deaf-blind children under 16 years. Before that the children had a rehabilitation counsellor who was only working in a home based program and those children were participating in the courses of other associations.

There are around 25 deaf-blind-children under seven years in Finland. Six counsellors who also work mainly in that unit in the program, visit the families, and try to contact local social, health and rehabilitation personnel in an attempt to organize better local service for the children. Each family receives two to four home visits each year and if needed, have more support. Three child care workers also work in the unit. Once in two years the children can have a period from a week to two months in that unit. Parents usually stay there for some days at the beginning of the period and two to three days at the end.

Between those long periods there are two week courses for parents and children together in which the other children of the families can also participate.

The main idea of that program is to support the families in ways to train and live with their severely handicapped child. Many of these families need a lot of psychic support and they need to learn how to communicate with their child. The main causes for deaf-blindness in Finland today is rubella and ushers syndrome. Ushers is a hereditary disease in which the child has a congenital hearing impairment and in the course of years they also develop the visual impairment of retinitis pigmentosa.

That unit has a very close contact with Institutions of Mentally Handicapped because many of these severely handicapped children have periods also there.

Institutes of Mentally Handicapped

Finland is divided into 14 districts and each of them has an institute. Usually the severely mentally handicapped children can receive services from there. Some children who are so severely handicapped that parents are not able to keep them at home all the time are placed there. Those children who are mildly mentally handicapped can obtain their first services from central hospitals, Central Association of the Blind and/or Unit for Deaf-Blind Children, but later they might be guided to have services from the institutions. But services for blind and deaf-blind children are also brought to the institutions by counsellors when they give lectures and have meetings with personnel working there.

The institutions also have their own counsellors in every commune who visit families of mentally handicapped children about once a week. She usually has a play hour with each child.

Financing of All Services

The social legislation guarantees that the families of visually handicapped children receive a service for their child regardless of whether they have or have not funds. The home visits as well as the courses are reimbursed by that legislation. When children are in hospitals the parents annually pay for 14 days and after the 14 days the expenses are paid. All low vision aids as well as other aids for the visually handicapped they receive free or on loan.

The parents can get financial support for a handicapped child who is taken care of at home until the child is 16 years old. For mildly handicapped that is about \$90 and for severely handicapped \$130. When a handicapped child is placed in a kindergarten group which she might attend only for rehabilitation, she can receive financial support from the local authority that pays the expense of the trips.

An experimental support has now been started for parents who attend different courses and meetings which will provide a daily allowance for those days they have been away from their work because of the handicapped child.

Where the Children Go After This Program For Children Under Seven Years

As already mentioned, when a visually handicapped child is six years old, compulsory education starts. Ordinary education starts when a child is seven years old. Visually handicapped children usually attend a kindergarten program to which they can go from home every day. If a child is going to attend a regular school in their own community the local authorities are informed about this very early (around two years before). This is so they can become orientated to accept and provide needed aids for the visually handicapped child. A local school can also send a teacher to a course organized by a school for the blind to gain more specific knowledge to teach the child.

Today there also are eight local itinerant teachers who visit children in local schools and counsel the teachers. Two teachers from that school for the blind are called integration teachers and they also visit children in the whole country.

There are today around 60 children going to the school for the blind and 270 are going to regular schools. About 20 of the 270 are totally blind. Children six years old and those already going to the school can have periods of one week to two months in the school for the blind if some special problems occurs. Those periods are called supporting periods. It is also possible that after some years a child may move from a local school to the school for the blind or the other way around. During school years the National Board of Education is responsible for these children but they also receive service from the Central Association of the Blind which receives expenses from the Ministry for Social Affairs. An educational counsellor organizes courses for children during summers, and these children can come whenever there is a need to a low vision clinic or to receive aids such as an optacon or brailier.

Parents' Associations

Both the parents of visually handicapped children as well as the parents of deaf-blind children have their own association. Within that association the parents organize different local meetings and camps. They also follow the development of legislation in social welfare and schooling and prepare statements to different officers. They do this sometimes on their own and sometimes together

with rehabilitation counsellors if they want some changes in the laws or in practice.

Summary

The purpose of the program for visually handicapped children is to identify and contact them as early as possible and to support the families so they can manage with their handicapped child. This helps the family find their visually handicapped child to be a child who can manage on her own in many different areas. The main idea is an early integration. It means that the parents of a visually handicapped child can find, not only special, but also local services.

You might also ask if there is enough support and education in such a total integration. We do not have to separate the children but real integration is when the children really feel themselves to be equal with other children.

69°

NORWAY

The districts
of Central
Hospitals;

5 University Central Hospitals
16 Central Hospitals

67°

U.S.S.R.

66°

65°

SWEDEN

Oulu,
a rehabilitation
counsellor for
children

64°

63°

62°

Kuopio,
School for
Blind, 16

Tampere,
a rehab. counsellor
for children

Jyväskylä
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found 1972
The unit for deaf-
children or

MAITTAUSALUEEN KARTTOJAINEN MAITTO



Low vision clinic aid center
Center based program and a rehab.
The Central Association of the Blind

VISUAL PERCEPTUAL PERFORMANCE OF
VISUALLY HANDICAPPED INFANTS

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Much has been written recently about the effects of binaural sensory aids on the development of young blind children. Several researchers have commented as well on the apparent increased visual performance of those subjects who have been exposed to binaural sensory aids, generating the theory that the auditory feedback from the device adds another dimension to infants' sensory perception which results in greater attention to visual stimuli and, thus, increased visual perceptual performance. The idea is an intriguing one. We know that:

1. Older visually handicapped children can be taught to use their vision better;
2. Kittens reared under continuous lighting conditions from birth evidenced an increase in dendritic spine density in the cortex, while kittens reared in darkness were functionally blind;
3. The visual cortex of kittens is similar to that of human infants; and
4. At least two infants diagnosed as totally blind and then exposed to binaural sensory aids were later diagnosed as having a great deal of usable vision, while many other infants have exhibited tracking, fixation, and convergence behaviors while wearing the binaural sensory aid.

Unfortunately, the binaural sensory aid research done in the past has made little effort to assess accurately the amount of vision subjects had before introducing the binaural sensory aid. Since the eye movements could be a result of orientation to an auditory stimulus alone, and not to any perceptual quality unique to binaural sensory aids, a study was undertaken to determine: (a) whether visual acuity can be measured in visually handicapped infants; (b) what stimuli or combination of stimuli visually handicapped infants attend to most; and (c) what effect, if any, binaural sensory aids have on visually handicapped infants' visual perceptual performance.

The study was conducted in two parts:

1. An eye orientation study, during which infants were exposed to 16 different combinations of stimuli, and the amount of visual attention to each condition was recorded; and
2. A visual perception study, where infants participated in pre- and post-tests of visual acuity and cross-modal transfer over an eight-week period, during which six subjects wore the binaural sensory aid for one hour per week.

Subjects. Twenty-four visually handicapped infants, ages 6 to 24 months, diagnosed perinatally as blind and visually impaired, from programs in Dallas, Texas, Erie, Pennsylvania, and Pittsburgh, Pennsylvania, participated in the study. Twelve were in the 6-12 month age range, and 12 in the 13-24 month range; 11 had been diagnosed as having one or more additional impairments; 13 were visually handicapped only. Visual acuities were not given on the eye reports, and in most cases, the children were reported as having light perception only. Bilateral cataracts and optic nerve hypoplasia were the most common eye conditions.

In the Eye Orientation Study, the following questions were examined:

1. Do infants attend longer to a visual-auditory stimulus than they do to a visual stimulus?
2. Do infants attend longer to moving stimuli than they do to stationary stimuli?
3. Do infants attend longer when binaural sensory aid information is available than when it is not?

-- Is there a difference in response to visual-auditory stimuli when BSA information is available:

-- Is there a difference in response under dark conditions when BSA information is available?

4. Do 6-12 month old infants respond differently than 13-24 month old infants?

Infants' eye orientation responses to four types of stimulus presentations (visual, visual-auditory, moving, stationary) were observed under both binaural sensory aids (BSA) and no binaural sensory aids (No BSA) conditions, in normal room lighting and in darkness. Subjects wore the BSA -- in this study, an Infant Sonicguide -- at all times, and the on-off knob was controlled by the investigator, as was the light switch. Each stimulus presentation occurred for 15 seconds, and the whole sequence was videotaped for later coding by independent observers. No subject received the same order of stimulus presentations.

Results from the Eye Orientations Study (see Figure 1) were not significant for any one stimulus presentation or combination thereof. While, on an average, more time was spent fixating to moving, visual-auditory stimuli, when both the Sonicguide and the room lights were turned on, the difference was not enough to be statistically significant. This is even more apparent when the darkness conditions are removed from the analysis (darkness was extremely difficult to obtain and still permit videotaping): (see Figure 2) Here, it is much more obvious that it makes very little difference whether the stimulus was moving or making sound, or whether the BSA was turned on or not.

There was, however, an interesting interaction effect, when the darkness conditions were removed: for infants who were only visually handicapped, fixation to a visual stimulus was greater when the Sonicguide was turned off, while fixation to a visual auditory stimulus was greater when the Sonic guide was turned on. It appears that the Sonicguide information was confusing in the presence of a visual stimulus alone, yet augmented fixation when a visual-auditory stimulus was present.

Responses in general were highly individualized. Subjects may have exhibited a personal preference, but no group pattern was evident. Mean responses ranged from 1.34 seconds for the multihandicapped 6-12 month old group to 5.90 seconds for the visually handicapped only 6-12 month old group; thus, on an average, subjects attended only 9-39% of the time. The apparent advantage shown by the visually handicapped only 6-12 month olds was not maintained by the visually handicapped only 13-24 month olds.

There is a tendency to attribute this performance to poor visual acuity in the first place. As the results of the second part of the study will show, however, subjects as a group had considerably more vision than had previously been thought.

In the Visual Perception Study, the following questions were examined.

1. Can visual acuity in visually handicapped infants be measured by the forced-choice visual preference test?

2. Do changes in visual acuity occur over a two-month period?

-- Do changes occur in both 6-12 month old infants and 13-24 month old infants?

3. Does 8 hours of exposure to binaural sensory aid information affect visual acuity over a two-month period?

4. Does infants' ability to use their vision change over a two-month period?

5. Does 8 hours of exposure to binaural sensory aid information affect infants' ability to use their vision over a two-month period?

A forced-choice visual preference test (FCVPT) was used to measure visual acuity. Infants were held by an adult facing the presentation stage or back panel of a three-sided portable chamber shaped like a learning carrel with a roof. One of a series of striped slides corresponding to several different acuity

gratings was projected onto the double screen on the presentation stage simultaneously with a homogeneous gray pattern of the same overall brightness. The screen on which the striped slide was projected was randomly assigned, and an observer behind and outside the testing chamber was required to determine on which side the striped stimulus has been presented for each trial by observing the child's behavior. The observer was not able to see the screen, nor could he or she see the corneal reflection of the stimulus. Each infant was tested with acuity gratings corresponding to distance visual acuities of 20/100 to 20/900 at a distance of 4 feet. Acuity was estimated for each infant when the number of correct responses was 66% or greater.

Results of the visual acuity test were significant for test administration: that is, subjects as a whole had better visual acuity on the post-test than they did on the pre-test. Subjects halved their visual acuities over that 8-week period. When the data was broken down by age and handicapping conditions, the same pattern was evident.

Two points stand out about these results:

1. Visual acuity improved regardless of the amount or type of "visual stimulation" and training the subjects received, the amount of intervention provided, or the training of the staff working with the child.
2. All subjects were capable of a great deal more visual response than had been previously diagnosed.

Six subjects from the Western Pennsylvania School for Blind Children's VIFTY Project were able to participate in a phase of the study designed to examine the effects of extended exposure to binaural sensory aids. The six subjects wore the Infant Sonicguide for one hour per week in each of eight weeks between pre- and post-test. No training occurred. A graduate student assistant untrained in binaural sensory aids visited each child briefly, placed the device on the child, turned it on, and continued with a natural play time.

The results show that the binaural sensory aid group performed better on the post-test than on the pre-test, but the changes in acuity were no greater than the changes occurring in all other infants. Extended exposure to the binaural sensory aid did not affect infants' ability to respond to the forced-choice visual preference test.

Another method of examining how well infants used their vision is by a cross-modal transfer test. In this procedure, infants were given one of two three-dimensional stimuli to hold for 30 seconds, and then it was removed from their hand. Both stimuli were then presented visually to the child, and the amount of fixation to each stimulus was recorded. This procedure takes advantage of infants' preference for novelty -- if subjects recognized the object when they were not touching it, they would spend more time looking at the object they had not held -- the "new" object. This procedure was included in the study with the rationale that while subjects' acuity might not change, their ability to utilize and interpret visual information might.

Results for subjects in this study were surprising: there was no effect for either age group or testing. In fact, subjects did poorer on the post-test than on the pre-test. When the extended binaural sensory aid exposure group was compared to all other subjects, it appears that being a member of the binaural aid group was advantageous:

BSA subjects did not lose as much ground as did all other subjects. On closer examinations, however, it was discovered that only two subjects demonstrated cross-modal transfer consistently. This appears to contradict earlier findings of improved visual perceptual performance found on the forced choice visual preference test.

If, however, the total amount of visual fixation during the cross-modal transfer test is calculated, without determining percentage responses to novel or

familiar stimuli, a different picture emerges. Here, there was significant effect for test administration. Subjects, as a whole, fixated on stimuli longer on the post-test than on the pre-test. This effect held for the extended binaural sensory aid group, which also did better on the post-test than on the pre-test, but no better than the group of all other infants. Subjects thus improved in their ability to attend to visual stimuli, but not in their ability to interpret tactual information when presented visually.

Conclusions:

1. All subjects increased their performance on measures of attention and visual acuity over a two-month period. This improved performance occurred regardless of age group, multihandicapping condition, amount of BSA exposure, amount of intervention, or the implementation of a vision stimulation program.
2. Subjects did not demonstrate cross-modal (tactual-visual) transfer. Only two subjects, both multihandicapped, demonstrated cross-modal transfer, in spite of the fact that sighted infants demonstrate cross-modal transfer at six months of age, and even though emphasis is assumedly placed on tactual development in visually handicapped and multihandicapped infants.
3. The binaural sensory aid in and of itself was not an effective aid in the development of visual abilities in this study. It seems clear that binaural sensory aids are not panaceas for young blind children. When compared to other perceptual factors, they were no better at eliciting attention than any other stimulus. When eight hours of exposure were allowed, no effects were evident.
4. No single stimulus factor or combination thereof affected the duration of fixation and visual attention in either visually handicapped only or multihandicapped subjects. Traditional theories of vision stimulation must be questioned as applied to visually handicapped 6-24 month olds. The amount of response is low, regardless of stimulus conditions and regardless of how subjects responded on both visual acuity and visual attention on other tests.

IMPLICATIONS

The assumption that visual stimulation affects the visual abilities of visually handicapped infants must be more closely examined. All subjects improved on measures of visual acuity and visual attention regardless of the amount or type of vision stimulation received. It is possible that the changes observed were due to maturation alone, or to the mere fact of intervention -- but in any case, no clear relationship exists between vision stimulation and improved visual abilities in infancy.

The assumption that visually handicapped infants readily adapt to impaired visual input by utilizing other sensory modalities must be questioned. For a long time, we have operated on the belief that blind and visually handicapped infants must rely on tactual and other sensory inputs to obtain information about their world. And yet this study seems to indicate that visually handicapped infants may not be able to utilize tactual input. More research is needed which examines stimuli of more distinct features, or familiarization periods longer than 30 seconds, and perhaps introducing grasp as a co-variable, in order to determine visually handicapped infants' abilities to take tactual information and relate to it visually. Until this question can be answered, reliance on traditional methods of educational intervention -- where the hands are used in isolation from other simultaneous sensory inputs -- must also be suspect.

Future binaural sensory aid research must examine several factors. The failure to establish the binaural sensory aid as a tool in the development of residual vision should be viewed in the context of (a) the Eye Orientations Study, and (b) the fact that no training was provided to subjects while they were wearing

the binaural sensory aid during the eight-week follow-up period. An analysis of eye orientation responses indicates that the binaural sensory aid did not precipitate overall greater fixation to stimuli, and that response to the binaural sensory aid appears to be highly individualized.

Finally, one of the purposes of this study was to distinguish the effects of the binaural sensory aid from the teacher variable -- i.e., how much of previously reported binaural sensory aid success in infancy has resulted from the involvement and interaction of an individual trained in and supportive of the use of binaural sensory aids, and, thus, able to reinforce and build on infant behaviors in response to the device? This study has shown that once the element of the instructor is removed -- when the infant is, in effect, left to explore the device's capabilities independently -- the binaural sensory aid has no effect on the visual perceptual performance of visually handicapped infants between the ages of 6 to 24 months. However, this study has not addressed questions of the device's effect when systematic training is provided, when developmental measures other than visual preference test are examined, or when the binaural sensory aid does not appear to be a prosthetic device, universally useful to all visually handicapped infants. The possibility remains that it can be a useful training aid for purposes other than promoting visual attention when used within a regular program of education intervention.

FIGURE 1

Mean Fixation Per Independent Variable^a

Independent Variable	Mean	Standard Deviation
<u>Method of Presentation:</u>		
Stationary	3.73	4.35
Moving	4.08	5.06
<u>Type of Stimulus:</u>		
Visual	3.64	4.52
Visual-Auditory	4.16	4.90
<u>BSA Condition:</u>		
BSA	4.22	4.80
No BSA	3.58	4.62
<u>Lighting Condition:</u>		
Light	4.52	5.04
Dark	3.29	4.29

^aIn seconds.

FIGURE 2

Mean Fixation Per Independent Variable

No Dark Conditions

Independent Variable	Mean	Standard Deviation
<u>Method of Presentation:</u>		
Stationary	4.45	4.55
Moving	4.59	5.51
<u>Type of Stimulus:</u>		
Visual	4.36	4.92
Visual-Auditory	4.68	5.18
<u>BSA Condition:</u>		
BSA	4.68	5.16
No BSA	4.36	4.94

^aIn seconds.

EDUCATIONAL TECHNOLOGIES AND METHODOLOGIES

FOR EARLY AGES:

PRESENT RESEARCH IN THE FIELD IN ITALY

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Since 1977 the National Council of Research (CNR) in Italy has charged our Center with the evaluation and experimentation of new educational technologies and the elaboration of methodologies for visually handicapped people.

Our efforts, from that date on, were devoted to investigating different approaches to the problem which involves many different competencies, from the electronic and technical to the psychological ones; besides, from the outset our main aim was to avoid an indiscriminate and random dissemination and utilization of any kind of technological product only on the basis of their newness and sophistication, or worse, for the uncontrolled publicity given to their marketing. In fact, it is unluckily very easy to persuade handicapped people of the usefulness of new aids for the solution of their problems, but it is very difficult to find instruments actually useful for an independent and autonomous life, for the development of educational and professional skills or to improve the quality of their mainstreaming and social integration.

During the last years a great deal of aids for disabled people were developed and commercialized, frequently at a very high cost all over the world, often without a scientific evaluation and verification of the benefits and the applications linked to their use in many kinds of activities. Consequently we decided to carry on our work always giving great importance to experimentation and evaluation of existing technologies to find out which of them actually gave the visually handicapped a chance to reach a level of approaching various vital functions equal to that of sighted people.

The second aim of our work was to set up suitable methodologies to teach and train handicapped individuals to proficiently use the aids; an investigation of the motivation, of the skills required for the task, of the most adequate channels of learning is here needed from the psychological and pedagogical point of view.

The third basic point we emphasized during our activity is what we call "the correct way to approach technologies": it's useless to provide handicapped people with educational technologies and it's impossible to get good results from them if they don't live in total integration with normal people.

This philosophy characterized our work, allowing us to choose which aids were really necessary and which superfluous; where technical problems had to be solved with technological aids and where they could be better approached with educational methodologies for early ages. In fact, it is wrong to believe blindly in the solution of the problems of the handicapped only by joining, in a deterministic way, the theory of integration and socialization, forgetting or underestimating the real difficulties that come out of a common life together.

It isn't sufficient to integrate blind children in state schools, in their families, in their social environments, to provide them with counseling services, and other social aids, if we don't pay attention at the same time to some important technical problems.

But it is wrong as well to suppose that a thoughtless shower of technologies may magically solve the real, specific, psychological problems of the visually handicapped: these problems must be faced with early intervention in their psychomotor, perceptive, cognitive, linguistic and social development in

the families and in the normal environment.

Nevertheless a "correct approach" to technologies is important, too, and sometimes, as we can see, necessary.

In this paper we will consider the aid for reading normal print in totally blind children (Optacon), an aid for reading and writing in partially sighted children (an Italian model of Closed Circuit Television) and a set of early rehabilitation methodologies for independent mobility.

The Use of the Optacon for School Age Children

Our activity with the Optacon started in 1972 with the experimentation and the evaluation of the possibilities offered by the instrument and the elaboration of a teaching methodology for adults. That was a period of social change, of new scientific approaches to handicapped people's problems and of strong criticism on traditional assistance in special institutes.

In this situation we considered the Optacon not only as a technological aid to reading normal print, but also as an instrument for the autonomy of the blind. In fact, our work with the Optacon accompanied and contributed to the progressive solution of the real, practical problems of mainstreaming and integrating our children and students in schools and society.

In 1976 the positive results obtained with about 98% of the students trained with our methodology convinced us to teach very young children and consequently to elaborate a new method and training manual for them, beginning with the first classes of primary school.

In a previous experiment we found out that children in the 5th grade, after 4 weeks of Optacon training, showed an increase in their desire for independence, cognitive progress and socialization. In this experiment 6 students were trained at the beginning of the school year with 4 weeks of specialized training and were later followed by the normal teachers in their Optacon use.

The teachers were very satisfied with the children's vivacity in learning and in their progress in socialization.

A manual for children had to develop their potentials of learning and cognitive development. The children needed short lessons and immediate, contiguous reinforcement and practical applications with positive feed-back.

We also wanted to adjust the methodology and the materials to the current methods used in the normal elementary schools, in order to allow blind children to learn and study side by side with the sighted ones. To be suitable for children we modified the adult manual, both in the content and duration of the lessons, with a progressive adjustment from the specialized methods to the normal ones.

We started by experimenting with 10 (6 to 10 year olds) blind and 60 (5 to 7 year olds) sighted children in a normal school. The alternatives to test were:

- 1) character recognition (directly from the print or introduced by manipulation of three-dimensional wood-blocks and objects of common use corresponding to the letters);
- 2) learning material organization (accentuation of the analytic or synthetic perception);
- 3) temporal standardization (intensive or slower training time).

Our tests stated that we must set up our training with:

- a) indirect presentation of characters
- b) synthetic perception
- c) fast pacing of learning

At last we obtained a manual that minimized the differences between specialized teaching of reading and normal teaching of reading. It was then possible to return the children to the normal teachers after two weeks of special

training.

A transversal research study compared 10 children trained by the normal methodology with 10 trained by the experimental one. The sample group with the normal methodology performed the training with a mean time of 68h and 40m, and an average reading speed of 13 w/m, while the experimental group scored a training time of only 39h and a reading mean speed of 10 w/m.

The significant time saved by the experimental group shows that we can reduce the time of specialized learning, letting the children gain independence and practice using the Optacon in normal class.

During the following three years we tested longitudinally the experimental group obtaining results of reading speed, accuracy and autonomy which showed a significant increasing rate.

Besides, according to the teachers, the results of efficiency were matched with better integration and socialization in the class during the school year.

Manual of methodology

The encouraging performances persuaded us to formalize the experimental methodology in a real manual which is now commonly used by our teachers.

The manual is printed in a "pica" type style (serif style), the letters are divided into nine groups to compose a word corresponding to an object, well known and easy to be recognized by touch by blind children.

These words are immediately presented as a whole, in order to follow the method of the "whole word" usually used in normal schools. Upper case is presented immediately after lower case.

The manual is used together with other didactic aids, as follows:

- 1) Object's presentation. Manipulation and analysis of the wooden letters (recognition and composition of the word)

The children have to recognize the real object, then analyze each of the letters which compose the word, using three-dimensional wooden letters, then recombine with the same letters the word corresponding to the object.

- 2) Board's presentation.

In this phase the children have to read the word first analyzed on a board where letters of rough texture are stuck.

- 3) Optacon reading of the word corresponding to the object.

The manual is firstly used here, and the word is read several times.

- 4) Presentation of the letters formed with raised dots.

This is an extra exercise to be used when any difficulty has been observed in the previous item to allow the children to realize the correspondence between a whole shaped letter and a dot-shaped one.

- 5) Optacon reading of single letters.

This is an exercise of recognition of the learned letters to favour assimilation and memorization.

- 6) Presentation of upper case letters.

Upper case letters are introduced using the same sequence described above (wooden letters, Optacon reading, recognition exercises).

- 7) Optacon reading of upper case and lower case together.

Recognition exercise.

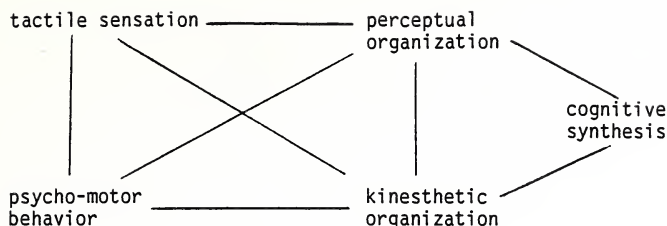
- 8) Optacon reading of words.

Words composed of learned letters are here presented. Some of them begin with the capital letter.

- 9) Optacon reading of sentences.

Reading of short and simple sentences (after the second group of letters) is amusing and stimulating for children.

It is impossible in our short time to give a detailed explanation of the theoretical learning patterns engaged in the set, but teaching and learning Optacon reading can be drawn as a process as below:



Perceptive-tactile, motor sensory and pure motor factors lead to the formation of kinesthetic and proprioceptive patterns, organized motor models (consequence of training) which allow a synthetic cognitive skill.

In a second research we tried to have a confirmation of the possibility/utility of teaching Optacon reading beginning at the age of 6, using the methodology described above and, at the same time we wanted to investigate eventual presence of negative transfer with Braille reading.

In fact the importance of Braille reading is not diminished by the existence of Optacon reading; on the contrary we usually teach Braille at first and Optacon after some time. But the two learning skills go on together and it seemed important to know if somehow Optacon reading technique might affect Braille reading technique.

Theoretically we can well assume a negative transfer impossible, because of the great difference existing between the two techniques: Optacon and Braille reading use different graphic symbols; different manual tasks: in the Optacon reading the left hand has a tactile perceptive task and is static, while the right hand has an explorative task, having to present correctly the letters; in Braille reading both hands have the same tasks (motoric and tactile perceptive).

Nevertheless we wanted to verify experimentally the possibility of learning Braille and Optacon without negative transfers.

Then we compared a sample group of ten children (6 to 10 year olds) who had learned Braille but not Optacon with an experimental group of ten children (6 to 10 year olds) who had learned both techniques. A test of Braille competency was administered three years after the Optacon training.

The results showed that the differences in the two groups regarding Braille reading speed were not significant.

Another test compared a sample group of ten children who were taught Optacon reading after the age of ten and an experimental group of ten children who received Optacon training at ages varying from 6 to 10 years.

The test was administered after 5 years of independent use of the Optacon.

The results showed that the Optacon reading speed of the experimental group was not significantly different from that of the sample group, while the increase in reading speed from the end of the training to the time of testing was significantly higher for the experimental group.

Use of CCTV in Early School Ages

In our activity of mainstreaming and integration we also had to face the problems of low vision. In fact partially sighted children need an educational approach profoundly different from that adequate to blind children; in spite of that, traditionally in Italy (and in the major part in institutional education) a great deal of partially sighted children were (and are still) trained with the same methods used with blind people.

This is particularly true for reading and writing skills. But vicinity to normal children and normal modes of learning strongly stimulated our students to emulate them.

Lenses, (loupes, microscopes and telescopes) were sufficient for some of our children, but a good number didn't succeed in reading and writing without a CCTV. That is the reason why we investigated:

- 1) Which kind of CCTV is the most suitable for school age children.
- 2) At what age we can (or need) begin the training.

As far as the 1st point is concerned, we realized that many types of CCTV were available, but most of them showed the following disadvantages:

- a) High cost (increased by the fact that all the systems were imported from abroad).
- b) Cumbersomeness of the equipment and its consequent non-transportability.
- c) Limitation of the objects and materials to be magnified.
- d) Difficulties in the use by young children (problems in focusing/magnification/brightness/contrast).

Consequently, we thought it preferable to try to elaborate an Italian prototype of CCTV which had to have the following characteristics:

- a) Low price.
- b) Modularity of the parts of the system (camera, monitor and x-y table) in order to allow the user to read with his own home television or school TV set, transporting only the camera and the x-y table (transportable in a light briefcase) and to make it possible to use the camera without the x-y table to watch things or materials different from sheets of paper.
- c) Ease of utilization, grouping all the functions in only two controls.

To approach point 2, we started from the evidence (resulting from numerous previous studies) of the delay existing in the achievement of the object concept in visually impaired children compared with normally sighted.

The search behavior, the object's permanence, the continuity of visual experience, seem to constitute critical "blanks" for the partially sighted which can contribute to create the above mentioned delay which can affect the birth of the concepts of classification and conservation.

Now, classification and conservation are two of the abilities most basic to the development of cognitive processes and, consequently, to the achievement of reading and writing skills.

Then, what we tried to do was to help visually impaired children to develop a functional manipulation behavior, providing them with a more effective eye-hand interaction to overcome the "blanks" we described above.

At the age of 5, every child has got his experience of prereading, but partially sighted children have often accumulated several difficulties in the transfer of object manipulation to object visual perception and, finally, to the object concept and its form as a graphic symbol.

In order to integrate all these activities, we thought to let the children have an easier eye-perception of the object during a) manipulation, b) comprehension of bright, simple, attractive picture, c) transferring of the meaning of the objects to symbolic and linguistic logic.

This can be obtained by a) presenting the real object taken by a camera and reproduced by a monitor at an adequate size, b) presenting the picture of the object and requesting from the subject the verbal comprehension of the same picture, c) presenting the picture and the name of the object linked by a continuous line.

The item can recall and sum-up search behavior, object's permanence and continuity of visual experience, giving the subject the chance to re-make (or to make first) these important tasks connected with the semantic meaning of the word.

In this manner the first parallels between real objects and symbolic logic comprehension are structured, and classification and conservation of

linguistic symbols are introduced.

We chose to use the whole word method, because, a) we decided to conform our methodology to that used by normal pedagogy in Italy, and b) because we verified that this method emphasizes the sound and the form of group of letters, presenting a more manageable task for children with impaired sight. Nevertheless, fluency might have been restricted because the analysis of words could result in a slower rate of accomplishment.

A combination of the whole word method and the part method seemed to be the most responsive to the task and the most suitable.

The next exercises reinforce the skills with the presentation of the graphic characteristic of the letters, firstly grouped for their intrinsic formal similarities and differences (classification) and secondly generalized for their printing incidence in the numerous different print forms (conservation).

First results of our research (that is still going on) seem to suggest that teaching the use of CCTV and allowing children to become familiar with it, can be of help in filling the gap often existing in the development of an efficient eye-hand interaction, and in creating the necessary parallels between object's concept and its symbolic graphic representation.

Education and Training for Independent Mobility: Early Rehabilitation Methodologies. (0-3)

Our center began to deal with psychological development of blind children at early ages and, consequently with rehabilitation when we realized, that most of the students we tried to mainstream showed problems that could have been referred to critical periods in their first infancy development.

Blindisms, spatial orientation and motor difficulties, problems in ego development seem to be the consequence of a not complete developmental process.

Another trend to begin this activity is the absolute lack of research and studies in the field in Italy and in the consequent need to discover a methodology of early intervention for assistants and parents.

Our early rehabilitation intervention has two major aims: on the one hand the exploration of kinesthetic and proprioceptive potentials as substitutes for visual perception, in order to promote and favour a faster reaching of the motor and cognitive stages which are not automatically acquired by the blind baby; on the other hand to stimulate the parents to understand the baby's real needs, giving them adequate information and counseling.

In fact, many studies in literature of early development showed that visual deprivation itself may not be the critical factor in producing the developmental lags we have cited above. Several studies discovered that more severe lags were observed in individuals who have experienced environmental deprivation than those who have experienced visual deprivation.

Many authors described the tendency for some parents of blind infants to engage in very little body contact with the baby. Another factor can be found in the parental overprotection which probably contributes to the more passive behavior of blind children.

Besides, very often blind infants presented prematurity or other perinatal complications which determined the necessity for a substantial period of incubation or other confinement to a hospital.

These situations obviously reduce the possibility of a normal psychomotor development (prevalence of the extended positions) and allow very few handling interactions with the mother, producing deficits not only in exploratory behavior, and related learning and cognitive functions, but also in the area of emotional development.

This is the reason why we tried to elaborate a methodology of intervention based on first, identification of the major deficits of the infants;

second, actual work with the babies; and third, work with the parents' and the infants' environment.

Our observations verified that besides the specific difficulties due to the visual problems, very often the parents happen to be frightened and worried about perinatal complications and the subsequent lags of the baby, becoming inclined to favour the establishment of irregular and incorrect feeding patterns, sleeping and waking rhythms, producing further problems in the infant's emotional development, and in its inner elaboration of the external world.

The second part of our intervention takes place twice a week with an approach that is different from the orthodox analytic observation and treatment: we think that the passive behavior of the blind babies makes it necessary to provide them with stimulations and active interest, at first with the simple, even epidermic relationship with the adult, then with objects, auditory and tactile cues, toys. It is not very important to find "special" games at this age: previous studies showed that the blind child needs, more than the sighted one, an active presence of the adults and how often its plays can become too simple and stereotyped if the adult doesn't play the role of auxiliary ego of the baby.

The place of intervention is alternately a resource room in our center or the baby's home. The setting is equipped with a soft carpet and various stimulation aids and toys placed in such a way to be easily reached by the baby.

Sometimes we ask the mother to be present, (especially during the first sessions) to favour the establishment of a positive relationship between the psychopedagogical worker, the baby and the mother herself, and also to avoid any interruption and on the contrary to better the diad mother-baby with this participation which can be after used for rehabilitation purpose.

The intervention starts with a clinical observation of the baby's spontaneous behaviors from the point of view of the psycho-motor, perceptual, cognitive and social development. Then the worker tries to intervene on these positive or negative behaviors.

Stereotypic behaviors have to be approached by gradually varying their forms, contents and meanings; stereotypes in fact constitute an obstacle for the integration of other functions and behaviors from the psycho-motor point of view and very often lead to isolation and sometimes to autistic behaviors from the social point of view, while, from the cognitive point of view, they prevent tactile and kinesthetic experiences and perceptions, limiting the search behaviors. Another field of intervention is that of motor automatisms (body balance, defense reactions) that are poorly used by blind children.

The stimulation of non-verbal communication gives rise to request from the baby.

To promote a slow and harmonious development the worker has to rebuild and to reach, later, stages which the baby has not yet achieved.

For example, very often blind children don't develop an adequate crawling behavior, even if other indications show that the children are strong enough to do so. We can assume this lack as a consequence of the different onset of the search behavior based on sound cues alone.

Then the intervention is to help the child to tactile exploration of its surroundings and to create a relationship between its body and the objects and between the objects. Crawling is not only a stage in motor development, but is useful also to the babies who can already walk to avoid anxiety when facing new or difficult motor tasks.

Written registration of each session is made and periodically (usually monthly) the work is discussed and syntheses are elaborated to be used with the parents.

Meetings with them take place every two months and videotapes are shown about the principal developmental stages achieved by the baby.

The evaluation of psychomotor development is done with a modified form of "Brunet - Lezine" test, the "Milani - Comparetti" motor development test and the "Blind Preschool Children Skills Inventory" of the Oregon University Project.

We are perfectly aware that our "applied" research is very limited and needs modifications in a wide range of subjects, but it was initiated with the aim of providing an answer to an immediate problem.

We need the growth of general systems of knowledge which can become a reality only if international connections between the workers in the field become more frequent and coordinated.

DEVELOPMENTAL PATTERNS OF NORMAL BLIND PRESCHOOL CHILDREN

ON THE REYNELL-ZINKIN DEVELOPMENTAL SCALES

FOR YOUNG VISUALLY HANDICAPPED CHILDREN

Glenn Larner
Joan Rowlands
(Australia)

INTRODUCTION

The Reynell-Zinkin Development Scales were published in 1979 in response to a clinical need to provide guidelines to professional people concerned with the developmental assessment and guidance of visually handicapped preschool children.

In developing the Scales, the stated aims were to explore those areas of learning and development considered to be particularly important for visually handicapped children and to plan programs which could be carried out by parents at home as part of their continuous daily interaction with their child. This type of approach, where the therapist acts as an "interpreter" between mother and child (Fraiberg, 1971), has been an integral part of the programs provided for the children associated with the Child Development Unit of the Royal Blind Society of New South Wales (Australia) for the past six years.

DESCRIPTION OF REYNELL-ZINKIN SCALES

In devising these Scales, Joan Reynell was particularly concerned by the lack of satisfactory developmental scales for babies and young children with severe visual impairment who were also likely to have additional handicaps.

No attempt was made initially to standardize the Scales because of the lack of a "standard" blind population, but by 1978 a sufficiently large sample of visually handicapped children had been assessed, using the Reynell-Zinkin Mental Development Scales, to establish age equivalents for the different stages of development in the areas assessed by the scales. It was also possible to make a comparison between the development of blind, partially sighted children on the different aspects of intellectual development.

The 109 children in the sample were described as partially sighted or blind depending on the presence or absence of visually directed reaching, approximately half of the sample falling into the "blind" group.

Although most of the children with severe additional handicaps, (described in a preliminary report in 1975) were excluded from this second sample, there remained a wide range of intellectual ability. An attempt was made to eliminate this variable by using Maxfield-Bucholz ages, derived from the Maxfield-Bucholz Scale for Blind Preschool Children, instead of chronological age levels for the visually handicapped groups. Developmental trends were plotted for each subscale for blind and partially sighted children, and age levels for sighted children were estimated from standardized scales for sighted children and checked by testing a small sample of fully sighted children on the Reynell-Zinkin Scales (N = 43).

The Reynell-Zinkin Developmental Scales were originally designed in two sections: a Scale of Mental Development concerned with areas of development thought to be associated with learning and having a mainly intellectual component, and a Scale of Motor Development - the divisions roughly corresponding to the Bayley (1969) Mental and Motor Scales for sighted children. At present only Part I, the Scale of Mental Development, is generally available, and this is the Scale now in

use in the Child Development Unit of the Royal Blind Society in Sydney.

DESCRIPTION OF SCALES OF MENTAL DEVELOPMENT

Five main areas of development were chosen as being of most importance to the intellectual development of children with severe visual handicaps, progressing from two months of age to a level of approximately five years.

The items in the Social Adaptation Scale are close to those items in the Maxfield-Bucholz Scale (1967) which have a large social component, particularly in terms of self help. To these a further qualitative breakdown allows areas of self help to be examined in greater detail. Joan Reynell felt that this Scale probably had the lowest intellectual component to all the five Scales described, as achievement on this Scale seem to be related to the amount of specific teaching given and its correlation with the other Scales was relatively low.

The Scale of Sensorimotor Understanding estimates learning in relation to concrete objects by manipulation, tactile exploration of textures, adaptive hand movements and the establishment of object permanence. There are increasing abstractions of recognition of size and shape - items allowing tactile learning to be assessed independent of hearing.

As the Sensorimotor Scale is concerned with objects within reach, the Scale described as Exploration of the Environment is concerned with the understanding of space surrounding the child, his orientation of himself and the objects he encounters during locomotion.

The Language Scales form the remainder of the test and comprise Verbal Comprehension and Expressive Language Sections. The stages in development of verbal understanding are based on Joan Reynell's Developmental Language Scales (1969) but whereas the sequence is the same she notes that the language-concrete link occurs later in blind children and the state of appropriate response to familiar phrases is more extended before the understanding of verbal labels occurs (Reynell-Zinkin 1975).

The Expressive Language Scale is divided so that there is a second part concerned with the ability to name objects, explain their use and describe simple actions.

PRESENT STUDY

The Reynell-Zinkin Scales have been used as an assessment instrument in the Child-Development Unit of the Royal Blind Society of New South Wales since March, 1981, and during that time forty-three recordings of blind children, with and without additional handicaps, have been made.

It very soon became apparent that our children were testing higher than the age equivalents suggested by the Scales, but in the area of expressive language particularly children in the Unit with serious additional handicaps were following the developmental trends for blind children, while the normal blind children were in several instances exceeding the sighted age equivalents. It was obviously necessary to explore this discrepancy.

AIMS OF THE STUDY

In spite of the small numbers available, it seemed important to try to establish how a "normal" blind child performed on the Reynell-Zinkin Scales, so that we could have a basis of comparison with other blind children who had no major handicaps.

It was equally important to attempt to answer the question most frequently asked by other professionals and parents: in a blind child with multiple handicaps, what degree of developmental delay can reasonably be ascribed to his visual impairment?

Clearly after two years all that can be presented is a pilot study, but

as this will be part of an ongoing service program it is hoped that it could be developed into a longitudinal study with sufficient numbers eventually to allow for statistical analysis and standardization of the Scales on a normative blind population.

METHODOLOGY

In order to examine the effect of blindness on child development we needed to confine our study to those children diagnosed as blind in the first months of life. We included the definition used in the description of the Reynell-Zinkin Scales - the absence of visually directed reaching - in our criteria for purposes of comparison. No attempt was made to define a "partially sighted" group: in our, admittedly limited, experience children in this group without additional handicaps showed essentially normal patterns of development.

Our criteria for inclusion in the study are tabulated (Table I)

Criteria for Inclusion in Sample

1. Total blindness or Tight perception only - absence of visually directed reaching.
2. Less than one year of age at referral to the Child Development Unit of the Royal Blind Society of New South Wales.
3. Age between 0-5 years at time to testing.
4. No other known handicaps or neurological abnormality.

TABLE I

DESCRIPTION OF SAMPLE

Only eleven children were included in the study but this is the total population currently associated with the Child Development Unit who met the criteria for inclusion.

All the children had been examined by ophthalmologists, pediatricians and members of the staff of the Unit to arrive at a consensus of opinion on the absence of other handicaps or neurological abnormalities.

The group consisted of four boys and seven girls.

Five children were first and only children, five were the youngest in the family. The only family in which the elder of two children was blind had a blind younger son (Table II).

Ordinal Position in Family

Only child	- 5
First of Two	- 1
Second of Two	- 2
Third of Three	- 2
Fourth of Four	- 1

TABLE II

With one exception, a baby who had both eyes enucleated at three months of age for bilateral retinoblastoma, all the children were blind from birth. The causes of blindness are shown in Table III.

Aetiology of Blindness

Optic Nerve Hypoplasia	- 3
Lebers Amaurosis	- 3
Retrolental Fibroplasia	- 2
(Both three months premature)	
Microphthalmia	- 1
Anophthalmia	- 1
Bilateral Retinoblastoma	- 1

TABLE III

It was thought that socio-economic factors and lower parental expectations might be a significant influence on the pattern of a blind child's development, particularly in the area of speech and language. Accordingly the distribution of social class in the sample, as estimated by the father's occupation, was examined (Table IV).

Social Class by Occupation of Father

7 Point Scale: Congalton (Australia) 1970)

<u>Social Class</u>	<u>Number in Group</u>
1	0
2	1
3	1
4	3
5	2
6	1
7	3

TABLE IV

The other "self-selected" variable brought to the study by the group of children in the sample was their geographical situation.

Although this becomes of less significance when home based programs are provided without charge to the families, it may, however, have a bearing on the availability of other support services (Table V).

Geographical Situation

Sydney Metropolitan Region:	6
More than 50kms from Sydney and Child Development Unit:	5

TABLE V

The range of age of initial referral to the Child Development Unit was two days to ten months (Mean = 5 months), the latter referrals being due in some instances to delay in diagnosis or occasionally to parents' inability to accept the implications of such a referral or the need for services.

All the children were living at home and had been involved in early intervention, relationship focused programs initiated by therapists from the Unit who visited at monthly intervals or more frequently if necessary. The therapist acted as advisor, program planner and interpreter of the child's management rested on the mother, father and other significant family members.

ASSESSMENT

The families attended the Child Development Unit only for the child's assessment and both his parents and therapist formed an integral part of the assessment process.

Eighteen recordings have been carried out on the eleven children in the study: five were tested once, five twice, and one three times over the past two years. The intervals between testing varied from six months to one year, depending at times, especially with country children, on the need to coordinate appointments with visits to other professionals.

The actual chronological age at which testing was carried out ranged from three months to five years, the earliest being adjusted for three months'

prematurity. Adjustment for prematurity was not made after one year of age.

RESULTS

With the exception of two recordings, as far as possible consensus on items passed was established at the time of assessment.

SOCIAL ADAPTATION SCALE (Figure 1)

On this Scale, which is concerned with the development of self help skills, the divergence between the developmental pattern for sighted and blind children is greatest between 1-1/2 - 2 years. This is also apparent in our sample, and although three recordings are at or above the range for sighted children, the majority fall between the curves for the two groups. With one exception those at or below the range for blind children are boys.

SENSORI-MOTOR UNDERSTANDING SCALE (Figure 2)

This Scale, which assesses sensory coordination, development of the concept of the permanence of objects and the relationship of objects to each other, is highly dependent on visual perception. Only one child in the group exceeded the ability of sighted children of comparable age, the remainder scattered between the two graphs, once again the boys being somewhat less proficient than the girls. The difference between the blind and sighted groups becomes less marked at the upper end of this Scale than that noted in the Social Adaptation Scale as cognitive development begins to transcend perceptual differences.

EXPLORATION OF THE ENVIRONMENT SCALE (Figure 3)

In this Scale which is concerned mainly with orientation in space and is dependent on mobility a similar trend noted in the previous scales is seen, but with an even more striking tendency for the boys in the group to fall below the age equivalents for blind children.

RESPONSE TO SOUND AND VERBAL COMPREHENSION SCALE (Figure 4)

The early items on this Scale are concerned with response to sound, including location and recognition, and goes on to the understanding of object labels and relating objects. On this Scale, with the exception of one boy and one girl both exposed to bilingual backgrounds, the comparative competence of the group is becoming apparent, and in four recordings the childrens' abilities are approximately equivalent to sighted children. Surprisingly, in view of the fact that some developmental language Scales give separate norms for boys and girls, the disparity between the sexes is no longer apparent in this sample.

EXPRESSIVE LANGUAGE SCALE (Figure 5)

The more superficial aspect of expressive language is measured by this Scale which extends from early babble to the ability to say words, phrases and eventually mature sentences.

The sighted and blind show an equivalent ability on the Scale up to the level of double syllable babble. After that, the sighted group move ahead and maintain a six to eight months gap. However, in the present study this gap is very little in evidence, and in eleven recordings the sample studied actually exceeds the ability of the sighted group, with again no obvious disparity between the sexes.

EXPRESSIVE LANGUAGE - VOCABULARY AND CONTENT SCALE (Figure 6)

Sighted children are said to start labelling objects twelve to eighteen months before visually handicapped children, accentuating the part vision plays in associating objects and verbal labels and thus enabling the child to use language

with appropriate understanding.

But our recordings show that the majority of children who have reached the age (15 months) to score on this Scale have maintained the competence suggested by their ability on the Language Structure Scale, suggesting that their language is not only fluent but appropriate.

DISCUSSION

It is obvious on examining our criteria for inclusion of children in the Child Development Unit sample that we are dealing with a totally different population of children from those whose performance on the Reynell-Zinkin Scales formed the basis of the original age equivalents.

It is a serious criticism of the Scales that inadequate data make real comparison impossible and the use of Maxfield-Bucholz ages instead of chronological ages to eliminate the "wide range of intellectual ability" is hard to justify (Figure 7).

Many of the "self-selected variables" (Warren 1976) of the population studied have not been described: the duration of blindness, aetiology of blindness, the proportion of blind infants at home or in Residential Nurseries, or other such significant factors which are particularly important in the development of a visually handicapped child.

In view of this we can only speculate on the significant variables that, particularly in the area of speech and language development, make the present age equivalents invalid for our client population - both of normal blind children and those with additional handicaps.

This paper is a preliminary report on a small number of normal blind children from which only limited conclusions can be drawn, but some interesting points have emerged.

In selecting the sample, all the children in the Child Development Unit who met the criteria were included and this resulted in a group comprising four boys and seven girls. Yet referrals to the Unit are consistently weighted towards boys in almost exactly reverse ratio at approximately three boys to every two girls, suggesting that significantly more boys than girls in the Unit have additional handicaps.

In examining the various sub-scales, there is no obvious explanation why the boys scored comparatively poorly in the "Sensorimotor" (performance) and "Exploration of the Environment" Scales, and yet conformed to the general ability of the group in the Language Scales where a difference in performance between sexes might have been predicted. Taken individually, and in each assessment evaluation of the total situation is essential - reasons may be found:-

One boy was the second of identical twins, weighing 900 grams at birth, who had retrolental fibroplasia. The elder twin was also affected, but less severely, and was developing well along normal lines. The parents' attention was therefore centered on the more handicapped infant who was consequently somewhat passive and over-protected.

Another boy was the second blind child in a family of two, of rather placid disposition with a very demanding blind elder sister so that it might be reasonable to suggest that he had less parental interaction than other members of the group. A third boy followed normal developmental trends in the first assessment, but a recent assessment two months ago demonstrated that he had made no gains in orientation and mobility in the past nine months, being still unable to move towards his mother's voice. Although he had adequate hearing for speech and language development, clinical observation suggested a significant hearing loss in the right ear, resulting in confusion in locating the source of sound and this is presently being investigated.

Ordinal position in the family showed a trend towards increased verbal

ability in single tones, and increased independence and mobility in those blind children who were the youngest members of families with normal siblings.

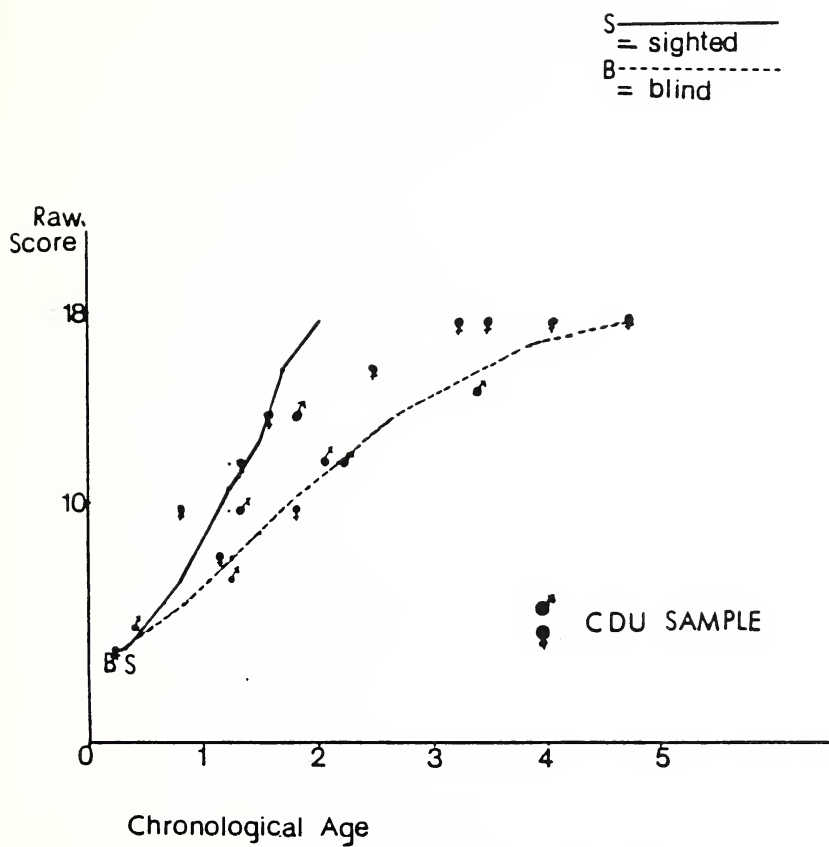
Social class proved no predictor of ability on the Scales as the four most competent children had fathers in occupations ranked as social class 2, 5, 6 and 7.

These observations point up the necessity of looking at all the factors surrounding the child during his development, including personality and acquired characteristics, so that assessments provide a synopsis of the whole child rather than a profile of achievements.

The Reynell-Zinkin Scale, devised specifically for visually handicapped children and not derived from scales of "normal" development, is obviously a well designed test concerned with developmental progressions rather than the acquisition of isolated skills. It is extremely useful in its present form for the program planning for which it was devised, but more data from a precisely defined normative blind population is required in order to derive reasonably valid age equivalents. Until then, in the language scales particularly, we can only use the norms for sighted children to give parents and professionals a minimal estimate of a child's ability and perhaps, with increasing integration of blind children into normal schools, there is some justification for doing this.

However, attempts to make blind children follow "normal" lines of development, as if they were simply normal children without sight, distorts any understanding of the particular contribution blindness makes to the child's total development. Nor can we derive this information from visually impaired children with multiple handicaps. Until we have an adequate picture of normal blind development, derived from sufficient numbers in well-documented, easily replicated studies, we will be unable to evaluate this contribution.

Fraiberg, Santin, Simmons and others have shown that, given different sensory equipment and therefore a different data base, congenitally blind children develop and organize their perception of the world in an intrinsically different way from sighted children. We do them a serious disservice not to acknowledge this and work at least as hard as they do towards an understanding of each other's "separate reality".



Social Adaptation Scale

FIGURE 1

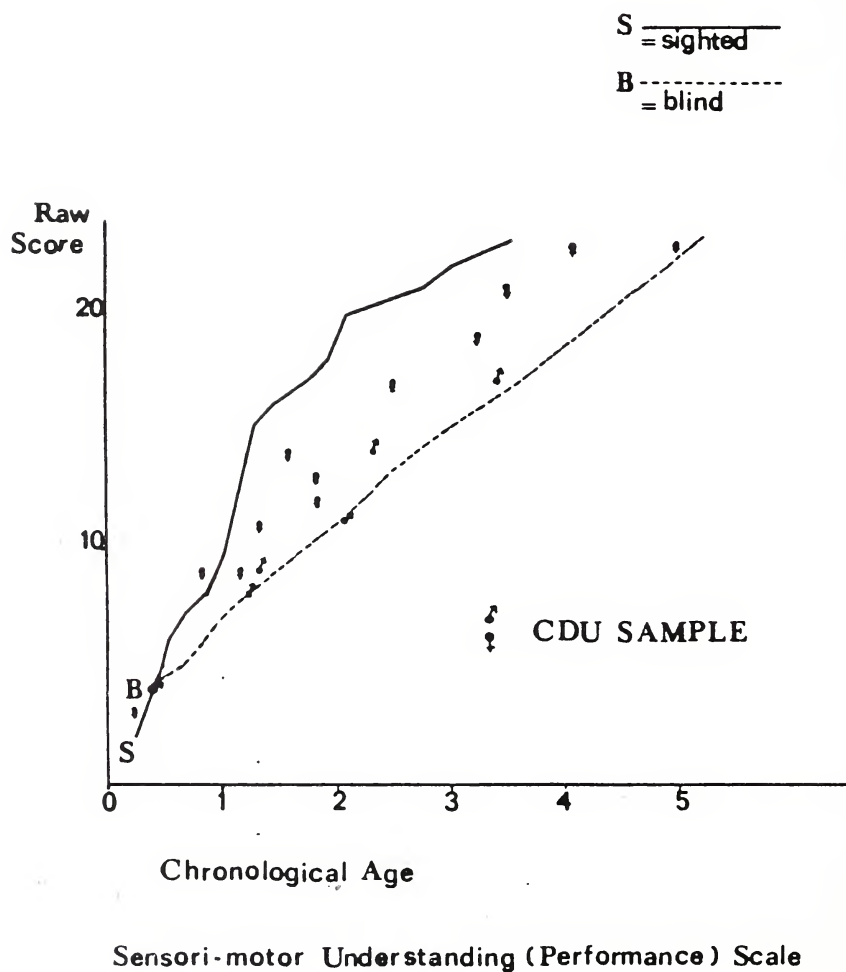
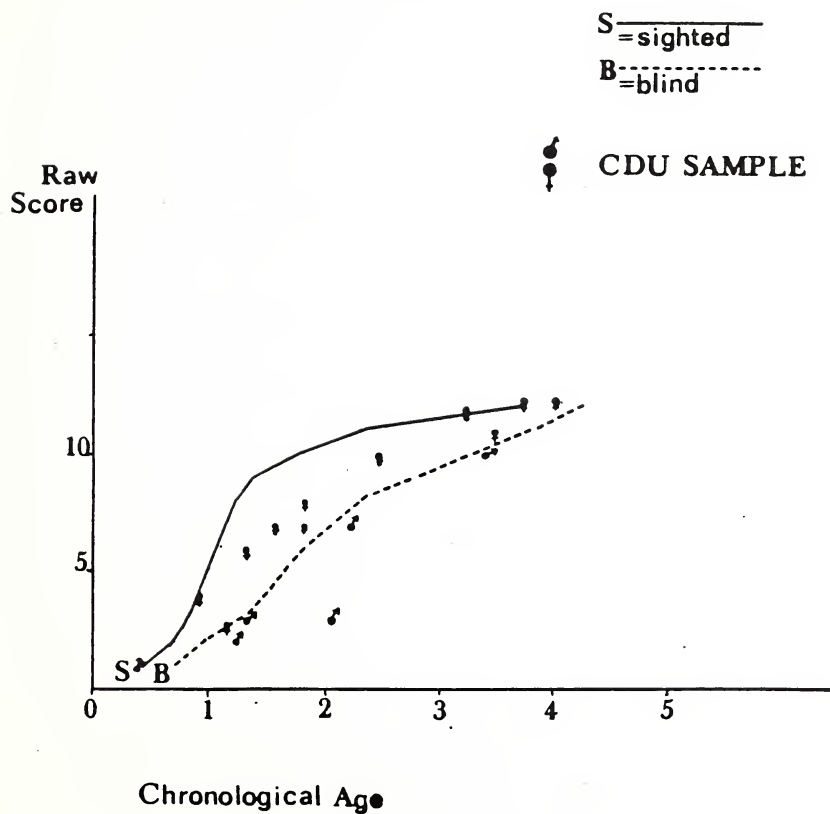


FIGURE 2

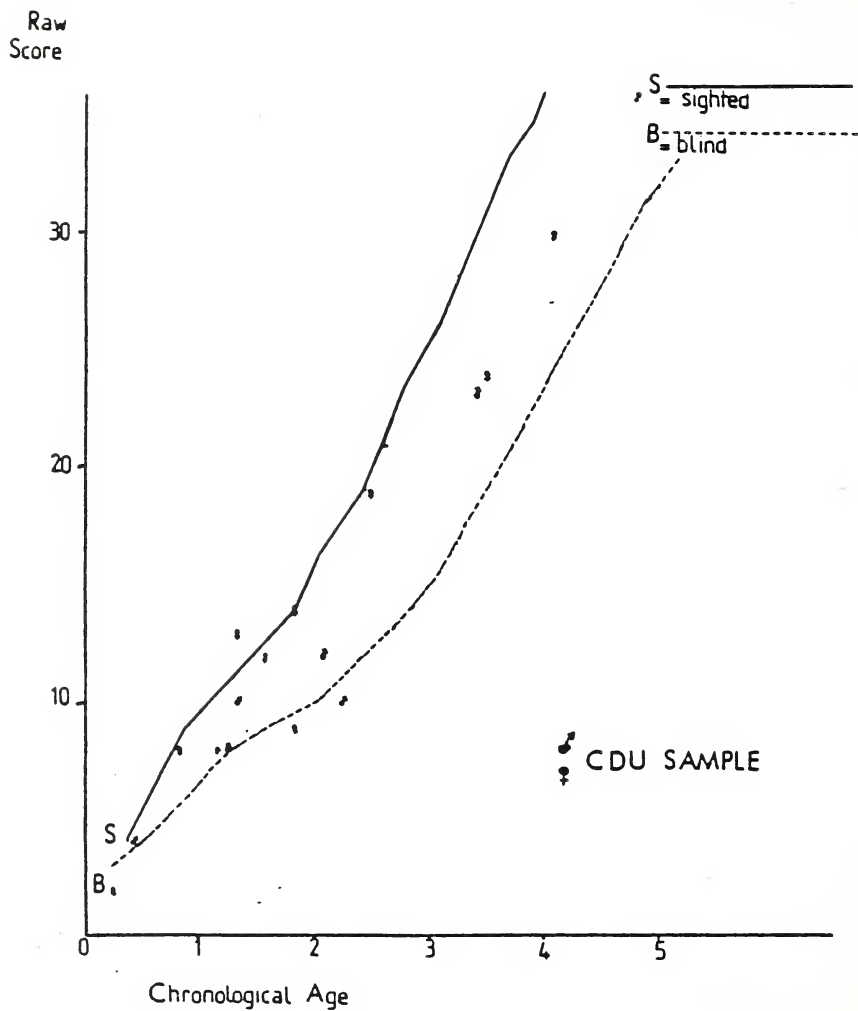


Exploration of the Environment - Orientation

FIGURE 3

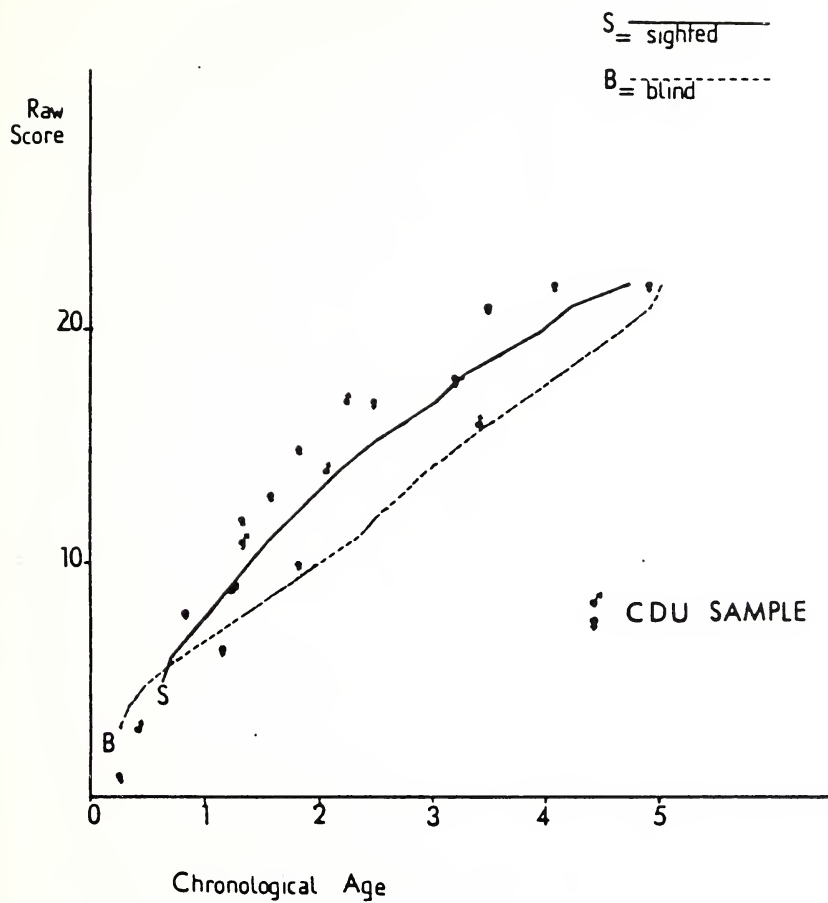
REYNELL - ZINKIN SCALES

90



Response to Sound & Verbal Comprehension Scale

FIGURE 4

FIGURE 5

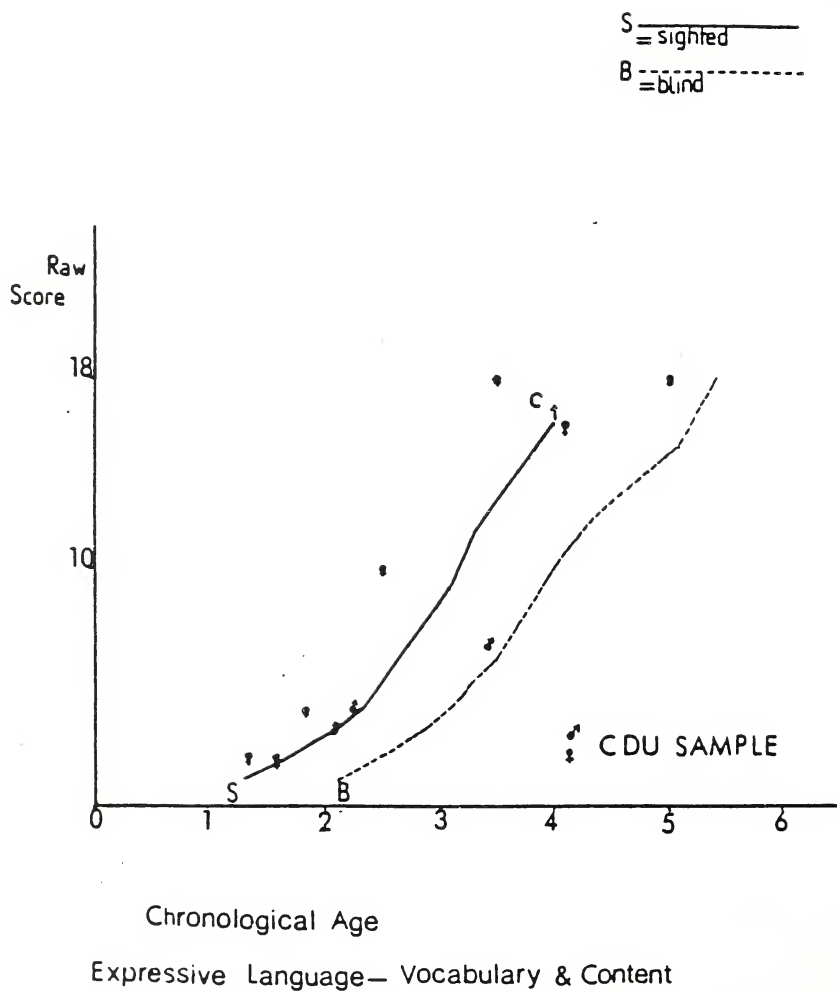
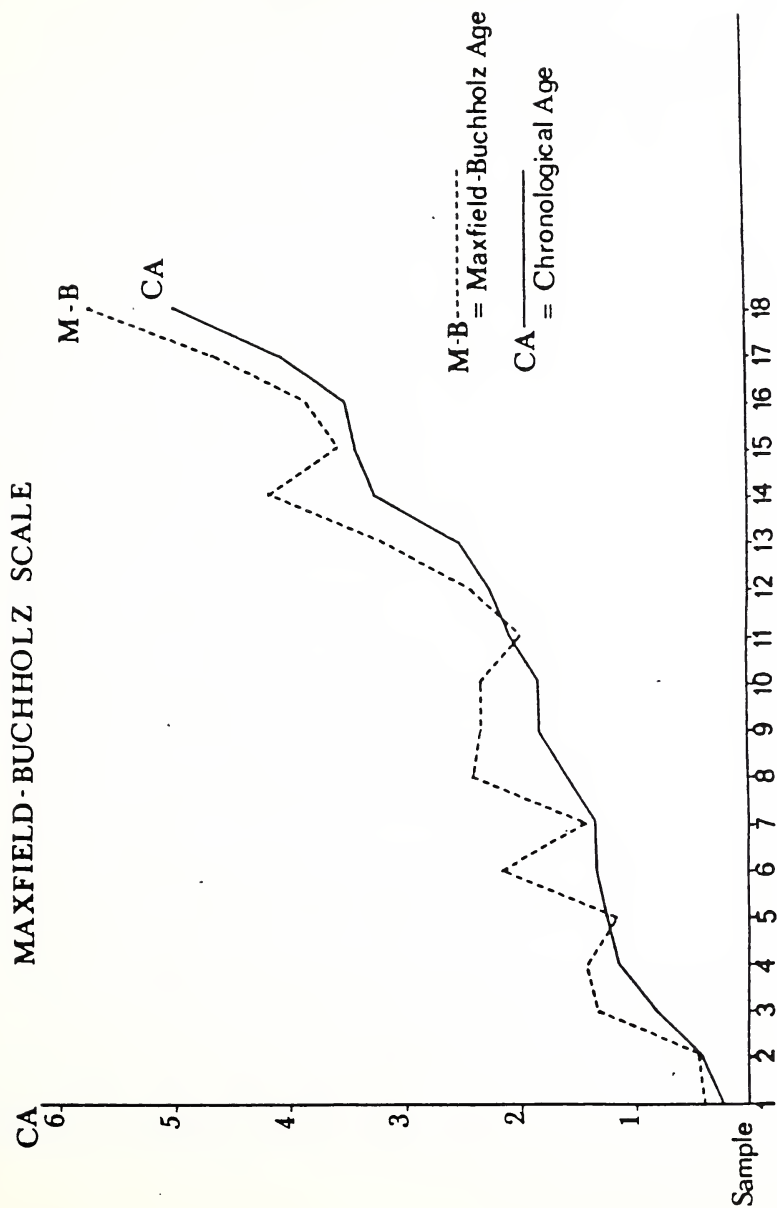


FIGURE 6



Comparison - Chronological & Maxfield-Buchholz Ages of Sample

FIGURE 7

1500 MILES BETWEEN STUDENTS OR ITINERANTINFANT SEVICES IN ALASKA

Nancy Crawford - Francine Kenney
(Alaska)

Geography, Transportation, and Climatic Conditions

It is impossible to describe and comprehend the type of service we provide for visually impaired infants in Alaska without first understanding the problems that arise due to Alaska's rather unique geographic, transportation and climatic conditons.

Geographaically the scope and variety of Alaska is rather astounding. In area it is one-fifth the size of the Lower 48 States. It covers 4 time zones and 586,400 square miles (1,524,671 square kilometers). There is a coastline that is greater than that of the continental United States encircling the state, and 5 mountain ranges within it. Alaska can be divided into 6 distinct geographic regions and people, with a population totalling only 400,000.

The geographic regions of Alaska are:

1. The Panhandle - a moist luxuriantly forested coastline that extends for 500 miles (805 Kilometers). The land area is approximately that of the State of Maine with a population of 60,000. Except for Juneau, the state's capital, fishing, lumbering, pulp processing and tourism are the main industries. The topography of the Southeast is that of steep glacier carved V-shaped valleys and rugged peaks. The many islands and rugged terrain makes highway construction between communities impossible so transportation is by air or sea.

2. Alaska Peninsula/Aleutian Chain - The Alaska Peninsula extends 550 miles/885 Kilometers with the Aleutian Chain reaching another 1,100 miles/1,770 Kilometers toward Asia. The Aleutians are fog shrouded, storm lashed islands of abundant rain and few people.

Military installations, weather stations, airports, and isolated fish processing settlements are home to about 3,000 Aleut Natives and about 5,000 military personnel.

3. The Great Interior - This area is cradled between the Brooks Range on the North and the Alaska Range to the South and covers a vast 166,000 square miles (431,600 square Kilometers). The largest city in the interior is Fairbanks, which is also the second largest city in Alaska with a population of 55,000. Mineral production, tourism, hunting, and being a supply center to the oil fields in the North are the main sources of income.

The climate of the region varies radically with rivers and lakes usually frozen from late October to April, with break-up in late April or early May, causing ice jams and spring flooding.

4. The Arctic - Arctic Alaska includes essentially everything North of the Arctic Circle. It is a place of nightless summers and sunless winters. The climate is harsh and the topography is that of rolling, treeless tundra. The shoreline of the region is that of the Arctic Ocean, which is ice locked 7 to 8 months each year.

The principle cities of the Arctic are Kotzebue with 2,000 people and Barrow with 2,400. The population of the area is predominantly Eskimo and hunting and fishing is a way of life.

Exploration in 1968 and 1969 revealed what is possibly the nation's largest oil reserves and the economy of this region is now based on oil production and tourism.

5. The Bering Sea Coast - Often called Western Alaska, this is a relatively remote land of a million lakes, ponds, sloughs, and rivers. Nome is the most widely known town. It was originally a turn of the century gold rush tent

city that now has a population of 7,200 and serves as a tourist and trade center for the mineral-rich Seward Peninsula.

The 200,000 square miles (520,000 square kilometers) of Western Alaska is home to 28,000 Eskimos scattered across the flat landscape in small subsistence fishing and hunting villages. Travel between villages is by boat or by air.

6. Gulf Coast/Southcentral - The Southcentral region includes the Kenai Peninsula, Prince William Sound, Cook Inlet, the Matanuska-Susitna Valley, and Alaska's largest city, Anchorage, which has a population of 200,000 - half the population of Alaska. Protected from the fierce Arctic weather by the Alaska Mountain range that parallels the coast, this region has become the social, financial, trade, farming and distribution center of Alaska.

Now that you have some concept of the vastness, and the harshness of Alaska, couple that with your awareness of what giving birth to a handicapped child can mean to a family.

Overview of Existing Service for Infants in Alaska

The birth of a handicapped child under the best of conditions is a traumatic experience for any family. Feelings of joy and excitement at having a new baby may be replaced by anger, guilt, frustration, disappointment and most of all uncertainty and fear. While the family is attempting to deal with their emotional response to having a handicapped child they are also looking desperately for someone to help train their child so that his handicapping conditions may be minimized.

Following the basic premise that early attention to delays in development can set a strong foundation to prevent further delays and encourage sequential skill development, the Alaska Division of Public Health in 1975 funded three Infant Learning Programs with locations in Juneau, Fairbanks, and Anchorage. In 1978, legislation was passed which authorized the Department of Health and Social Services to provide guidance and financial assistance to organized groups of parents, nonprofit corporations, school districts and regional educational attendance areas in providing special services and training needed by exceptional children, birth to 3 years of age. The programs established were to emphasize individual needs and where possible, be home-based and involve parents in the education and training of their children. Since 1975, 15 programs have been added, bringing the number of programs to a total of 18 and the total enrollment is now over 500 students. Currently programs exist in Anchorage, Homer, Barrow, Sitka, Ketchikan, Eagle River/Chugiak, Kenai, Fairbanks, Petersburg, Kodiak, Palmer/Wasilla, Dillingham, Nome, Juneau, and Bethel.

Many of the above mentioned programs serve areas outside of the communities in which programs are located, so that approximately 40 rural villages are served by these programs.

Unlike programs for the older child with a diagnosed or clearly identified developmental problem, the Infant Learning Program seeks to identify and serve infants who have developmental delays or who are at risk for later disabilities.

The Infant Learning Program accepts referrals from medical personnel, community health or social service agencies, school districts, and parents themselves.

Following a referral, a teacher contacts the parents and schedules a home visit to:

1. Provide parents with information on the Infant Learning Program.
2. Get acquainted with the child and family.
3. Discuss parent concerns and expectations.
4. Gather information about the child's history and development.
5. Obtain consent and agreement forms.

6. Explain and receive written permission to conduct a developmental assessment.
7. Schedule an appointment to conduct a development assessment.

After a developmental assessment, the child may be enrolled in the program which usually consists of weekly visits of 1 to 2 hours in length. Activities during the home visit are specific strategies designed for the family to carry out with the infant at home. They are geared toward the accomplishment of specific goals and objectives in the infant's IEP. The IEP is developed by the teacher with input from other professionals where indicated and the parents.

Special Education in Alaska is mandated at age 3, so as the child approaches his third birthday, the Infant Learning Program contacts the local school district when appropriate, to arrange for a meeting with the parent and district representative to share information and to provide for a smooth transition. In those cases where special education at age 3 is not necessary, the teacher may facilitate transition to local head start or preschool programs.

In addition to the local Infant Learning Teachers, 2 Consultant Programs based in Anchorage are funded to serve hearing impaired and visually impaired infants. These programs provide direct and consultant services on an itinerant basis to any local Infant Learning Program which expresses the need.

Francine has given you an idea of the immense size of Alaska and the sparsely and widely distributed population. You will remember that half of the population live in the Anchorage area. Given this background you would expect to find a proportionately small number of infants who are visually impaired living throughout the state, and this is so. In the last year our program has served 60 infants and their families in 19 locations.

We, Francine and I, are the teachers for the Alaska Infant Learning Program serving visually impaired infants from birth to 3 years of age. We are both trained as teachers of the visually impaired and in addition, we hold certificates in Early Childhood and Elementary Education. Francine is also an Orientation and Mobility Specialist and has training in teaching the severely and profoundly handicapped. Our program is coordinated by Jane Brodie who also coordinates Alaska's Blind/Visually Impaired School-Age Program.

Most of the infants we serve are referred to us by an infant learning teacher. Usually the Infant Learning Teacher has already made several visits to the home and is suspecting a visual impairment. Before contacting us she will administer a screening device that was prepared by our program and, based upon these results, she will send us a referral requesting assistance.

After a referral is received and has been assigned to Francine or me, we will contact the Infant Learning Teacher to arrange a joint home visit. During this initial visit, we will provide the parents with information about our program and receive permission to assess the child's functioning. We will also gather information about the infant's history and development which, along with our screening information, will help us to determine if our services are needed.

Occasionally referrals come from ophthalmologists, pediatricians, public health nurses, and the parents themselves. In this instance, our program will make the initial visit to the home to gather information to determine if our services and/or the services of an infant learning teacher are warranted. Regardless of which program receives the initial referral, if the infant is determined to have a visual impairment, joint home visits are arranged between the consultant for the visually impaired and the infant learning teacher.

During these joint home visits we assess the infant's visual functioning and developmental skill levels, provide IEP recommendations, assist in the implementation of objectives, model specific strategies for parents, and provide parents and infant learning teachers with a variety of resources, aids and reading

materials, as needed or requested.

After the infant is assessed, a Memorandum of Assessment is prepared that includes a listing of the instruments of assessments and the areas assessed, the results of the assessment, and the recommendations to be included in the infant's IEP. As a result of the assessment, the amount of our involvement and the frequency of future home visits is determined.

Following each home visit, Home Visit Summaries are written and sent to the parents and the infant learning teacher; occasionally we are requested to send our reports to the child's physician. The report will include a summary of events, activities and observations, conclusions and suggestions for the parents and the infant learning teacher. Between visits we maintain contact by telephone with the parents and the infant learning teacher.

Prior to each visit, we contact the infant learning teacher to plan the joint home visit. When the infant learning teacher or a public health nurse requests a multi-disciplinary evaluation, we participate in the Professional Evaluation Review along with the other members of the team that may include pediatricians, psychiatrists, nurses, audiologists, speech and language specialists, physical therapists, occupational therapists, and infant learning teachers. These evaluations, funded by the Department of Health and Social Services, ensure the selection of appropriate goals and objectives for the infant's IEP.

In addition, we often accompany the parent and child to ophthalmological examinations to provide the physician with educational information as well as to serve as support for the parents and to help interpret medical information. This is a role we also assume when an infant is hospitalized.

As youngsters near their third birthday, we assist the parents and the infant learning teacher in locating and evaluating the preschool programs that are available. With the parent's permission, we will meet with the preschool personnel to provide the child's current assessment of developmental levels, the past programming, and our recommendations for future services. This may be part of a school district's Child Study Team process.

Youngsters turning three years of age continue to receive services from the Blind/Visually Impaired Program's school-age consultants in all but four school districts in Alaska. This greatly facilitates the transfer of services as the children enter school. The four districts: Anchorage, Fairbanks, Kenai and Matanuska-Susitna, all have their own teachers of visually impaired. Services to youngsters in these districts may be continued for 6 months after the child's third birthday or until the child is officially enrolled in an appropriate school program.

At present, Francine and I, with help from Jane, are providing various degrees of service to approximately 40 infants and their parents in 19 locations throughout Alaska. Over 50% of these infants live in communities that can only be reached by plane and rarely do more than 3 infants live in a single location. When we visit a location we will usually stay in a location more than 1 day.

Delivering service by plane in Alaska, especially in winter, adds its own set of problems. A lot of our time is spent waiting for planes that may not arrive, over-flying destinations because the weather does not permit landing, hoping that you will be met at the airstrip by truck or snowmobile and always being prepared to be weathered in by carrying with you additional food and clothing.

The goal of the Blind/Visually Impaired Program is to provide monthly on-site joint home visits but this has not always been possible even in the Anchorage area where homes can be easily reached by car. We have found it impossible to see 20 infants each month when so much time is consumed in traveling. In addition, we receive about three new referrals each month which require an initial screening visit. To meet these difficulties we have developed a priority system to determine infant services.

Our first priority of services is for infants birth to 18 months of age whose vision is their primary disability. Our goal is to visit these youngsters once monthly. Initial referrals are also a top priority and Jane helps us by screening those youngsters we believe will require limited services. Our second priority of services is for infants over 18 months of age who exhibit no developmental lags as well as the severely multi-handicapped youngster whose vision is not the primary disability. These youngsters are seen once every 6 weeks to 2 months. Our third priority of services is for infants who are medically fragile or at risk for later disabilities. These infants are generally monitored by telephone and visited every three months.

Before I conclude this description of Alaska's Infant Learning Program for Visually Impaired Infants, I wish to emphasize one point: we appear to stress our services to infants, yet we truly believe that the parents are the most important factor in a visually impaired child's growth and development. For this reason we believe that all services and programs must provide the parents with the knowledge and skills to enhance their feelings of competence. In addition, we recognize that parents must become their child's primary advocate and that we, as educators, must provide them with the information and support they may require to fulfill this role.

EARLY VISUAL DEVELOPMENT
NEW KNOWLEDGE CALLS FOR NEW PRACTICE IN THE
TREATMENT OF VISUALLY IMPAIRED CHILDREN

Eva Lindstedt
 (Sweden)

During the last decades it has become possible to investigate the early visual development of infants by new methods. The importance of early stimulation has become evident.

"Looking and seeing" is a complex performance accomplished by several visual functions which are developed at different periods during the first months of life. Vision is developed from a low level by the combined influence of maturation and experience. Deprivation of experience (stimulation) during a particular sensitive period may retard the development and make impossible certain steps of development.

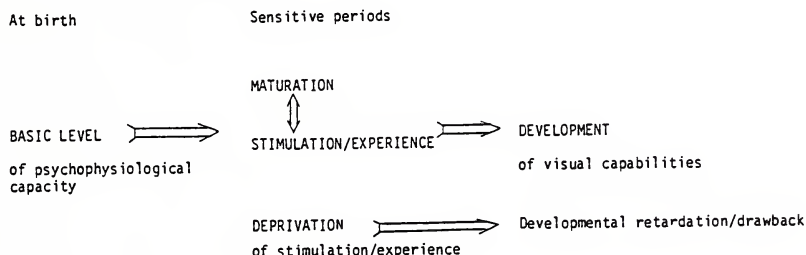


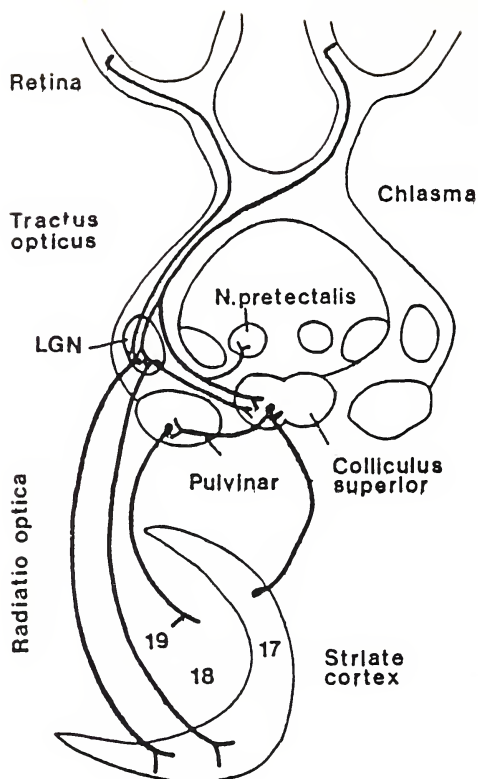
Figure 1

How much does deprivation of stimulation influence development?
 Which functions are the most sensitive?
 How long is the sensitive period?

Basic research

When considering early visual development, interest is focused on the developing cortical and subcortical functions involved in visual perception. Of course also the condition of the eye and visual pathways is important. The transparency of the optical media of the eye, the optical qualities of the cornea and lens, the condition of the receptor cells and ganglion cells as well as pigmentary cells of the retina, are fundamental. These are the structures creating activities in the retina, transforming the light patterns into nerve impulses, which are transmitted by nerve axons on through the visual pathways to the middle brain, from there by new channels further through thalamus to the visual cortex.

Figure 2



Optic pathways in the brain. Fibers from the nasal retina cross in the chiasm. Retinal ganglion cell axons extend to the lateral geniculate nucleus (LGN), to the superior colliculus, and the pretectal nuclei. LGN projects to area 17, and the superior colliculus to the pulvinar, the pulvinar further to area 18 and 19. Area 17 also projects downward to the superior colliculus.

(after Hyvärinen and Hyvärinen)

Experiments on animals; implications for the human being.

Visual cortex

Since the 1960s the Nobel prize winners David Hubel and Torsten Wiesel have been investigating the physiology of the visual cortex of cats and monkeys. They have shown that cortical cells normally receiving information from both eyes will lose their function if one eye is occluded or otherwise disturbed during the early sensitive period of the animal's life. If the abnormality is corrected after the period of developmental sensitivity has passed, the function is not restored.

is visual loss in the infant, development will suffer, consequently. If, for some anatomical or functional reason, the monkey baby suffers deprivation of visual input, the cells of the visual cortex will not receive stimulation and their normal growth will be influenced negatively. If the sensory input later is made possible the cells may be unable to react. The sensitive period has passed.

The associative centers likewise are influenced by early loss of visual input. Here other sensory modalities may use cortical cells and connective channels, which normally would take care of visual information. If the visual input is restored at a later date, the cells may be unable to change their preference of reaction and promotion of visual perception may not be achieved.

The implications for the visually impaired child are obvious. It is necessary that the visual information to the visual cortex and associative cortical centres becomes as good as possible during the early sensitive period of the infant's life. This means, e.g., that surgical treatment of cataract or optical correction of refraction errors has to be given very early in order to make possible an optimal visual development. If there are impairments of the eye or visual pathways, which cannot be treated, the visual input might be augmented by making the visual stimuli stronger. E.G., a dystrophic retina may be presented with sharper, brighter and magnified images, so that the visual information may become strong enough to elicit response and reaction in the visual cortex and associative centres.

To make all this possible we need knowledge about the eye, the possible means of ophthalmological treatment and optical correction. In addition we need to know the visual capabilities of the individual child. We must be able to measure each failing visual function (visual acuity, visual field, contrast sensitivity, colour vision, light adaptation, etc.), analysing the residual vision and decide how to make use of it optimally. We also need to know when and how stimulation should be given and what the expectations would be.

Early development of visual performance

The visual performance relies upon several visual functions which are integrated with oculomotor and other motor functions into complex systems of function with different maturation age. Visual perception includes analysis (in the visual cortex) of spatial contrast and linear orientation making up the perception of "form". This "form" perception has to be completed by other perceptive and emotional qualities added through the cortical associative centres.

A pragmatic aspect of visual performance may help in understanding many traits of a child's development. What is vision good for? How does the child use his vision?

Three kinds of "aims" may be considered:

- 1) Orientation/mobility. For this purpose the child uses perception of space and detection of shape and form of objects. The spatial contrast and linear orientation of objects are analysed and the position and location of objects, including the child himself, is perceived. Locomotion is initiated to reach objects detected and located in the space.
- 2) Information of detailed visual quality of objects. To make this possible visual resolution (acuity) as well as colour vision is used. Discrimination of fine details needs good resolution and also the ability to keep the visual object projected on the part of the retinae particularly fit for discrimination tasks, i.e. the macula. The neuro-oculomotor reflexes make the fixation possible.
- 3) Visual signals. Visual objects perceived in the peripheral field as a rule are not actively noticed. If, however, the object seen gives rise to

mental or emotional attention, the oculomotor system is activated, the direction of gaze changes and the image of the interesting object becomes located in the macula where it may be studied for visual details. The child turns head and gaze, fixating the object. This function, so very fundamental and frequently elicited during a child's development, contributes tremendously to make the visual experience rich and varied. It plays an important part also for the general development of the child. A child who, because of defects of the visual system, is deprived of these visual signals may suffer retardation of motor or mental development. Passivity and "autistic traits", often seen in the visually impaired child, may also follow.

The first types of visual tasks mentioned, i.e. orientation-mobility, detection of shape and form, rely particularly upon certain visual functions as contrast sensitivity, perception of linear orientation, peripheral vision. If these functions are preserved to a certain degree, the child will manage also if the visual acuity is very poor.

The second type of visual tasks, discrimination of visual details, on the contrary, is very much dependent on the visual acuity. Oculomotor functions are important as well: ability to fixate, vergence, accommodation capability.

The third performance, reaction on visual signals, depends on visual peripheral field and a functioning visuo-oculomotor reflex system. Of course it requires some amount of psychic attention, which might fail in the retarded infant.

Visual function - Development, assessment and stimulation.

Contrast sensitivity and perception of linear orientation are poorly developed at birth. The maturation is rapid during the first months of life and the sensitive period probably short. This means that space and form perception has to be developed early in life to become good. If there, for some reason, has been deprivation of visual stimulation during the early months of life there is little hope of restoring a retarded development later in life. This accounts for disappointments with regard to visual improvement, e.g., after surgery of congenital cataract.

Visual acuity also is poorly developed at birth. The development is rapid during the first months, but the sensitive period seems to be prolonged and consequently some improvement may be induced by stimulation at a later date.

It is to be noted that a short sensitive period means that the period during which deprivation is threatening the development, is also short. If the sensitive period is prolonged the period when deprivation may cause retardation or regression of development is longer.

Figure 4 - Early development of some visual functions

CONTRAST SENSITIVITY

low spatial frequencies (perception of crude form and space)	0 -- 6 months
high spatial frequencies (perception of fine details)	0 -- 3 years

VISUAL ACUITY (RESOLUTION)

newborn	6/200 (0.03)
-- 3 months	20/200 (0.1)
-- 6 months	6/20 (0.3)
-- 2 years	6/6 (1.0)

What has been said above has great implications when we consider how to handle treatment and stimulation of visually impaired children. During the first months of life the stimulation primarily concerns development of perception of space and detection of crude forms. Later visual acuity becomes the most important function to be stimulated.

Something has also to be said about the visual sphere of the child. During the first months the child sees only the objects located close to him and stimulation is better performed at near distance. During and after the second month the visual sphere normally widens and now perception of space is accomplished. Visual acuity and visuo-oculomotor functions develop both on far and near stimulation, but near vision tasks are the most effective. So again, we have to take care of the close surroundings of the child. What is said of the visual sphere of the normal child is still more appropriate in low vision children. The mentally retarded child may be retarded also in the sequence of visual development.

Good assessment methods are essential. Infants and small children cannot be assessed by ordinary "vision tests", which are as a rule prepared with the aim of measuring visual acuity of grown ups with rather good vision. Objective methods may be used, but are of limited value in assessing visual performance. Lately behaviouristic methods have been used with great success, sometimes in combination with objective methods.

The preferential looking behaviour is innate and is found also in the premature baby. The child is able to fixate a visual object and also prefers one object before another. The type of object preferred differs during different periods of development and may tell about the maturation age of the visual system and also of the mental maturation of the child. The newborn prefers high contrast targets with simple geometrical patterns (type black-and-white stripes or squares). Such patterns seem to give the highest "reward" or sensory satisfaction to the immature visual system, stimulating the cortical cells the best. A pattern is always preferred before a plain surface. As the visual system matures, and the visual capabilities of the child raise, he/she learning spatial orientation, detection and discrimination, there is a sudden shift in preference. This shift as a rule takes place between the fifth and seventh week of life, the child then developing preference for more complex, coloured patterns, rich in details.

Preferential looking can only take place if and when the child sees the objects. It is possible to measure the perceptual threshold of the child if he is forced to choose between two objects which are graded and controlled. In this way the method has been used by several researchers in combination with other methods to assess very accurately different visual functions as contrast sensitivity, visual acuity, colour vision and stereovision in infants.

The method has also proved valuable for the study of psychological and emotional development of the child. Preferential looking used as a method for assessing visual capabilities is most reliable in infants below the age of 9 months or such a mental age in retarded children. Modified and complemented by operant technique it may also be used in toddlers and older retardates.

The optical system of the eye plays an important part for the visual performance. Detailed visual tasks can only be performed if the optical system of the eye presents the visual system with sharpe and detailed images. The proper development of the visual acuity depends upon the optical quality of the "visual input". Thus the refraction of the eye is important, as is the capability of the optical system to accommodate, i.e., to change the refractive power when required in fixating on different distances. The refraction power is easily measured by retinoscopy in cycloplegia (i.e., after the pupil is dilated and the ciliary muscle paralysed). The procedure is time consuming and requires the cooperation of a skilled ophthalmologist or optometrist. It is

inconvenient for screening purposes.

Photorefraction is a new method recently introduced for large-scale screening. This method only picks up children with considerable refraction errors, inequality of refraction or squint. These are the children the most threatened with regard to their visual development, however. Correction with lenses or glasses should be prescribed immediately. Any postponement will influence the visual development negatively. One method of photorefraction can also be used without cycloplegia and then may measure the accommodative capability. This is very important with low vision children, who very often (particularly if their visual acuity is below 6/60 or they suffer from nystagmus) have a poorly working or failing accommodation in near vision. Unfortunately the equipment for this method is not yet available. Indirect methods may be used, as the comparison of visual acuity for far and near. Very often the acuity for near is found to be reduced compared with acuity for far. If the child is furnished with plus lenses to account for a failing accommodation, the result will tell that the child now is able to use his residual visual acuity fully also in near vision tasks.

When working with a child stimulating near vision it is evident that the correct refraction has to be attended to. The correction should take care not only of a refractive error but also of a failing accommodation. For children with considerable visual acuity reduction the rule is: Use additional plus in their glasses in near vision tasks. Bifocals may be used very easily also in small children.

The fine visual tasks and also visual signals can only be performed if the oculomotor system is functioning. There is a close relationship and mutual influence during development of visual and oculomotor functions - fixation, stable gaze, smooth movement, following, scanning, convergence, binocular comitance, accommodation. In low vision coordination and refinement of oculomotor function may suffer considerably, this in turn influencing the developmental events, favoring one visual function, suppressing or retarding another. Very often, in low vision children, fixating capability is weak or its development delayed, scanning may be poor, there may be nystagmus and/or squint.

When attending to a visually impaired child, it is important to investigate his/her oculomotor capability. Surgery may be effective to reduce nystagmus or squint. Training may promote fixation or scanning skill and alternative technical methods in using vision may be introduced, e.g., moving the visual object instead of moving the eye in scanning.

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ANATOMICAL AND PHYSIOLOGICAL FACTS AS A BASE FOR EARLY REHABILITATION

OF BLIND BABIES

Dr. Yael Ben-Dor
(Israel)

Blindness is not the failing of one single sense, that of sight, but is a syndrome that affects the entire early development of the child. This has wide-spread implications, and his intellectual, emotional, and motoric development, including speech, is decisively influenced and/or retard by blindness.

Understanding of the complexity of the syndrome and its physiological and functional consequences will explain the necessity for earliest rehabilitation of a blind child.

Scientific research on the development of specific brain centers by stimulation has shown that the increase of brain cells depends on the amount of functional stimuli received. Conell proves in his microscopic-anatomic "Atlas of the Brain" that brain cells (neurons) and their connective nerves (axons and dendrites) multiply rapidly during the first three months of life and increase more slowly up to three years if stimulated normally and continuously. If not, few or no brain cells develop, a fact that was proven by animal experiments: cats and dogs are born blind. They develop sight during the first two weeks of life with fast increase in neurons in the brain due to optic stimulation. If their eyes are covered during the first six weeks so that no optic stimulation occurs, neurons in this specific brain center do not increase. Their number remains low for life, even if afterwards their eyes are open and do receive optic stimuli.

Programming of a computer is the base of its functioning and so is the programming of the brain, but with a difference. Many brain functions are pre-programmed and transmitted by the genes from generation to generation, as for example, mother-instinct or homing of pigeons, etc.

In addition to these pre-programmed functions, extensive programming of the brain is added during the first period of life. This programming is most important and governs such as eye-hand coordination, physical responses to sensory stimuli, and many others.

In case of malfunction (loss of certain brain centers, or senses) faulty programming results. Blakemore placed two groups of newborn cats in rooms with horizontal respective vertical stripes. When exchanged after a few weeks, they lost their orientation in space to such an extent tht they were unable to walk or to run. This faulty programming remained for life, as it would also in human beings.

These facts are of utmost importance. Any motory or sensory rehabilitation is based on replacemnt of missing functions by stimulation or neurons in other brain centers and on new programming of the brain. The best results can be obtained in the first months of life, when brain cells still increase readily and rapidly. Later rehabilitation is, of course, always possible, but slower and less complete.

Sight is composed of a variety of functions which are by no means all absent in the blind.

Sight begins with the transmission of an image as received by the optical media of the eyes. The image is conveyed by the optical nerve to a series of brain centers. Inversion of the received image, interpretation of this image, completion of the partial picture, elimination of unimportant details, analysis of color, comprehension of the image within the frame of the whole picture or situation, transmission to memory and speech center, 3-dimensional interpretation, estimation of distance and size, association and recognition based on past

experience are all part of the seeing process.

Even the blind, who lack the ocular reception of the picture or object, can still develop a great part of the above functions, partly by other means, such as touch, hearing, or association. But again, let us stress, it is of the greatest importance that these functions are developed in earliest childhood. This should occur in all cases even if there is only the slightest suspicion that the child has sight defects or is blind; time should never be lost while waiting for a definite diagnosis.

Now we will examine additional functions of sight. Orientation including awareness of direction and space as well as the sense of balance are also functions of seeing. A normal person can demonstrate how these functions are dependent on sight if he tries to walk, run, or jump blindfolded. This dependency becomes even more evident if he tries this outdoors or on uneven ground.

The person with sight orientates himself unconsciously by vertical and horizontal objects. He is aware of direction by looking at distant objects (e.g. trees, church steeples), he estimates distances with the help of known sizes (e.g. people, houses). This process is unconscious and takes place within a split second.

It follows that one must start mobility training as early as possible in order to develop orientation in space which is not dependent on sight. All exercises and games which develop an awareness of the body, posture, direction, and position are as important as grasping, crawling, running, walking, and jumping. Later on, orientation will be developed- both indoors and outdoors- by ball games and sports.

The importance of acoustic functions is great. In most countries early education in acoustics for blind children is neglected despite its decisive importance.

A baby with normal sight already reacts in the first weeks actively to visual stimuli. He turns his head, lifts himself up when he sees something, he reaches for the bottle or for his hand, and later he turns himself around or crawls in order to grasp an object. The blind child does not receive these optical stimuli, which lead to active movement. He reacts passively to acoustic stimuli, he listens perhaps, but he does not react to it with active movement.

Blind children, who have not received early acoustic training, lift their heads much later than children with sight. They also crawl considerably later and play much less. This delay in development can and should be compensated for by intensive early training in acoustic discrimination. This facilitates later training in mobility and is crucial for the optimal development of the speech centers in the brain. Special attention should be paid to impairment of hearing in one or both ears, and intensive audiological investigation should be made in every case of optical impairment.

Daily living skills do not only demand coordinated movements but also the coordination of different brain and sense functions. The above explanations are relevant here. The earlier the training in cleanliness, self-care, proper eating habits, dressing, etc., the better the results.

It is a great pity that there are not enough skilled workers to teach children and parents alike intensively. This is true not only in Israel, but also in several European countries.

For the blind child, the rehabilitation program centers on development of all remaining senses, inner image by feeling and touch, acoustic training, including listening, evaluation of direction and distance, orientation in space, also of body and extremities in space, equilibrium, development of any sense or ability that replaces partly and in combination with other senses his lack of optic reception.

Early psychological help for the parents is essential, and so is the

active cooperation of the family in the rehabilitation program. Rehabilitation should start immediately, at the moment the mother or anyone else suspects impaired vision, without waiting for a final diagnosis from the eye-clinic. No damage is done by stimulating development, but the damage may be serious and irreversible by postponing rehabilitation even by a few weeks or months.

If the blind child has an older brother or sister, the upbringing will be much easier than with a first born or an only child. The mother already has experience, she knows at what age a normal child starts to grasp, to crawl, or to talk, and so she will unconsciously encourage her baby to do the same. Siblings also help to stimulate the blind child from the beginning. He hears them talking, running, playing more or less noisily, and also quite naturally they will play with the baby or include the toddler in their activities.

And now a few words about psychological advice for parents of blind children. The better the parents are psychologically adjusted, the more they can help their handicapped child. However, this help should be reduced to a minimum. Education for independence and self-help is the best way to prepare the child for life. It should be emphasized that help for psychological problems is equally important for children born blind as for those who become blind later in life.

In conclusion, let us state the following facts:

1. About so-called hardware: the increase of brain cells (neurons) takes place mainly in the first three months of life. This process is almost finished by the age of three years.
2. About so-called software: the connections between neurons develop over a longer period and can be strengthened by contact with other brain cells.
3. The increase of brain cells and their connections are dependent on external stimuli. Without stimulus the cells do not increase and their function is limited.
4. As a result of stimuli and training, other brain centers may be used to improve the existing or replace the remaining functions. The earlier this happens, the better the results.
5. Rehabilitation through listening and hearing as well as the development of body and space awareness and the introduction to play should start in the first weeks of life.
6. Optic and auditive testing, cochleography, EEG and ERG for early diagnosis of sight and hearing impediments should be undertaken immediately at the first suspicion of the mother, doctor, or anyone else to enable the earliest treatment. Also, even if there is some doubt, intensive training should begin without any delay.

Most countries have either not recognized the importance of early treatment of children with sight- and hearing- impediments, or they have, but for a variety of reasons they have not taken steps to implement it. In most places treatment is confined to monthly psychological advice for the parents. Many places have also not realized that it is cheaper to rehabilitate the handicapped child early and thus enable him to be independent later, than to wait and then find that lifelong institutions and sheltered work places must be provided.

We, the sighted people, together with the parents of blind children, should try to compensate the children for the difficulties arising from their handicap. These children have a moral claim to get help for their full development so that they can use all their potential to achieve independence and the highest possible grade of education and profession.

SOME DEVELOPMENTAL COMPLICATIONS
ASSOCIATED WITH RETROLENTAL FIBROPLASIA

Stuart W. Teplin, M.D.
(U.S.A.)

Introduction

I had the opportunity to attend the Retinopathy of Prematurity Conference in Washington, D.C., about 18 months ago. One of the most interesting aspects of the conference was the fact that retinopathy of prematurity, or retrolental fibroplasia (RLF), is a disease entity which was supposed to have disappeared in the late 1950's, and yet today remains a very real risk for our premature infants, and remains the subject of a number of controversies. In that forum of national and international experts, there was intensive discussion and often debate about such issues as pathophysiology, diagnostic criteria and terminology, preventive measures such as vitamin E, surgical procedures, and ophthalmologic outcomes.¹

There was also controversy about the current incidence of RLF. Retrolental fibroplasia was first noted as an entity in the earlier 1940's as neonatal intensive care units became well established in university centers. During the 1940's and early 1950's in the United States, RLF became the leading cause of blindness in children. As seen here, the discovery that oxygen was a major etiologic factor led to a sharp decline in its incidence. However, as technology has advanced and made possible the care and survival of even smaller and gestationally younger premature infants, many centers in the United States have anecdotally noted an alarming trend toward the increasing incidence of RLF again during the past decade. In 1965, a nationwide survey found that RLF accounted for approximately 9% of all blindness in preschool children.² In 1979, it was estimated that 546 infants in the United States became blind due to RLF.³

Another area of interest has been the development of young children who are blind due to RLF. This topic provides a framework by which we can look at several issues together, particularly the problems of how blind children manage to acquire competence and information about their world and how this might interact with biological and social complications of prematurity. Previous studies on the development of RLF children during the 1950's and 1960's were inconclusive, but pointed to the possibility of mean I.Q. being at or slightly below that of various control groups,⁴⁻⁸ and also that RLF children appeared to be at increased risk for emotional disorders, including autistic behavior.⁸⁻¹²

Subjects and Methods

Over the past five years, I have had an opportunity to evaluate and longitudinally follow the developmental progress of over 35 severely visually impaired infants and young children. These were seen either as part of an interdisciplinary evaluation at the University of North Carolina's Division for Disorders of Development and Learning or through North Carolina Memorial Hospital's follow-up clinic for high-risk newborns. Of these children, 13 had retrolental fibroplasia. And of these, three had grossly adequate near vision in at least one eye. The remaining ten children with RLF, ranging in age from ten months to 4 1/2 years at this time, all with either total blindness or vision of only light perception, make up the group that I would like to describe in more detail at this time. In following these children along, I sought to look for various biologic and social factors and in developmental patterns, and I wondered whether these might correlate in some way to the severity of overall developmental handicaps.

The following is a brief review of some of the preliminary findings and a discussion of how patterns of early development of blind children are illustrated by this small group of modern day RLF infants. First I will describe some of the perinatal characteristics of these infants and review some trends in their developmental progress. I would then like to show some brief videotapes of two or three of the children, illustrating some of the major issues. I will conclude by discussing some of the physical management issues important in helping these children and their families.

On figures 1 and 2, I have summarized several important perinatal characteristics of the ten blind RLF children. Figure 1 includes those born in 1978 and 1979; on figure 2 are those born in 1980 to 1982. Birth weights ranged from 670 to 1470 Gms. (mean birth weight was 1000 Gms.); and they were born at a mean gestational age of about 28 weeks. Only two infants had five minute Apgar scores greater than 6. Of the ten infants, six were males and six were white. The mean duration of initial hospitalization was approximately 135 days, and the babies required oxygen for a mean of more than four months.

Almost every baby had multiple perinatal complications, the most frequent of which were respiratory distress syndrome, bronchopulmonary dysplasia, apnea and bradycardia, and jaundice. Four of the babies required exchange transfusions, including two (#4 and #5) requiring six and 13 exchange transfusions respectively. Other complications included patent ductus arteriosus and asphyxia. Two infants had significant intracranial hemorrhages (#3 and #7). These two, as well as two others (#2 and #9) developed hydrocephalus. Only one infant (#9) was discharged from the nursery with known severe neurologic impairment, e.g., still requiring tube feedings at six months because of absent suck.

Each child's medical, growth, and neurodevelopmental status were observed over time. Also, I became familiar with most of the families and their ways of coping with their children's handicaps.

Eight of the ten children had anywhere from two to four developmental reassessments over time. Their ages when last evaluated ranged from ten months to 4 1/2 years (age adjusted for prematurity). Their developmental progress was checked primarily by using the Reynell-Zinkin Scales. These mental developmental scales which were standardized for blind and visually handicapped young children, are comprised of five main subscales, considered by its authors to be most important for the intellectual development of visually handicapped children. Each scale has items ranging from early infancy to about five years of age; these focus on: (1) self-help and social skills (Social Adaptation), (2) learning related to manipulation of concrete objects, including understanding object permanence (Sensory Motor Understanding), (3) the child's ability and interest in orienting himself and objects in space, beyond his immediate reach (Exploration of Environment), (4) the understanding of words and language (Response to Sound and Verbal Comprehension), and (5) expressive language, including both the structure and content of verbalizations.

Results

Figures 3 and 4 are summaries of the current visual and neurodevelopmental status of the ten infants. Those four children with the most severe handicaps are case #1 (severe communication handicap), case #3 (cerebral palsy and mental retardation), case #7 (functional mental retardation), and case #9 (profound mental retardation and cerebral palsy).

Of note is the finding that of the six normal or only mildly handicapped children, only one (case #8) showed normal language development. In fact, case #8 is clearly showing the most normal developmental outcome of the ten infants. In figure 5 her developmental progress is plotted, with chronologic age along the horizontal axis and developmental age along the vertical axis. As

noted, her progress in all five areas has consistently been above average since about six months of age.

Of the eight infants on whom there is specific longitudinal data from the Reynell-Zinkin (all except cases 2 and 6), four infants have shown an overall normal rate and level of development, although these scores fail to take into account some of the behavioral and social problems that these children had. Also, the language scores on this test sometimes failed to account for the rote quality of their language.

In contrast, figure 6 shows the plots of the developmental course of two (cases 1 and 7) of the four children with more significant additional handicaps. The other two multiply handicapped children (cases 3 and 9) both have severe cerebral palsy and even slower developmental progress.

Conclusions

It is difficult to extract from the follow-up of this very small group of patients any obvious conclusions. However, the following are some cautious observations from this group:

(1) It is likely that children who are blind due to RLF make up a very heterogeneous group, some of whom are normal to above average in overall functioning, some of whom are severely and multiply handicapped (probably secondary to extreme perinatal hazards), and many with normal or near normal potential, but with frequent association of milder additional handicaps. This heterogeneity and high incidence of associated handicaps is seen also in all blind children, regardless of etiology.

(2) Three factors appear to be more consistently associated with risk for more severe handicap: first, all four of the severely handicapped children are males. Secondly, all four multiply handicapped children were delivered following a history of maternal placental abruption or prolonged rupture of membranes. These maternal conditions were seen in only one of the six relatively normal RLF children. Thirdly, three of the four severely handicapped children had evidence of either a grade IV intraventricular hemorrhage or brain infarction and hydrocephalus. Only one of the six more mildly affected infants had hydrocephalus. I was unable to see any obvious difference between the mildly versus severely handicapped children in birth weight, gestational age, days of hospitalization, days of oxygen, Apgar scores, or the ability to perceive light.

(3) In this small, possibly skewed sample of children, even those with generally normal developmental progress tend to have language which is somewhat rote and echolalic in quality. Perhaps this is the precursor to the so-called "verbalism" often seen in blind school-aged children.¹³ It is difficult to know, without further study, the degree to which this could be minimized with more intensive early language intervention.

(4) These RLF children are very sensitive, as are most blind children, to both the positive and negative influences from their environment. My subjective opinion is that in these children, these factors appeared to have significant effects on their language, behavior and socialization skills.

Case Examples

I would now like to illustrate some of the important issues that are associated with the development of blind children with RLF. We should keep in mind that these are probably just as crucial for children whose blindness is due to any other condition.

Rodney (case #7) is now a 2 1/2 year old boy who is one of the more severely handicapped children of the group studied. He was born into the toilet at home at 27 weeks gestation, weighing 800 grams. He had the longest

hospital course of all 10 of the infants (a total of almost 18 months, primarily because of severe chronic lung disease). Over the past year, he has been hospitalized 7 times for acute pneumonia. His parents are financially poor, poorly educated, and unemployed. There are 5 children including 3 under the age of 3. They are obviously a very caring family, but have often been unable to follow through on suggestions for promoting Rodney's optimal development. This is partly due to Rodney's chronic fatigue.

A major problem for Rodney has been a vicious cycle of chronic fatigue, undernutrition, and chronic infection. He is severely growth retarded in weight and height. Also alarming has been slowed brain growth, resulting in absolute microcephaly. In the past, developmental progress has been limited by not only whatever brain damage may have been caused by severe perinatal hazards, but also, to a large extent, by his chronic tiredness, recurrent lung infections, and lack of consistent parental and teacher expectations (see figure 6B).

The first videotape segment shows a physical therapist working with Rodney (age 2 1/2 years) to try to overcome some of his very negative feeding behaviors. One can easily see how frustrating feeding Rodney can be for his parents. The second segment was taped 2 weeks later, after daily intensive intervention by this therapist. Therapy was successful, largely because of the therapist's consistent, firm expectations and verbal rewarding for eating efforts. Significant progress was made, and since this was taped 3 months ago, Rodney has continued to feed better, gain some weight, and also achieve new motor and language milestones.

The next videotape focuses on the parents of David (case #1), another of the more severely affected children. Following an initial hospital stay of 75 days, he went home, but was readmitted two days later because of apnea, requiring an additional month in the hospital. The parents later described this period of time as "Hell", for they were never sure David would survive. Then, when it finally became clear that he was going to live, they discovered (several months later) that he was blind. Their reactions to these problems were typical of many parents of RLF children,¹⁴⁻¹⁵ and reflect their own feelings of guilt, anger, and frustration. David's major handicaps, other than blindness, have been a severe communication and language problems, behavioral tantrums, and autistic behavior (see figure 6A).

In the first portion of this videotape vignette which was taped when David was 3, I had just been talking to the parents about David's severe behavior problems and the parents' ineffectiveness and frustration in dealing with this. This is followed by an interview with David's mother one year later, after David and his family received more intensive help through his new preschool and a parent support group. This illustrates the positive effects of such support and intervention on parental attitudes which were reflected in David's much-improved behavior.

In summary, these 10 cases of blind children with RLF illustrate the extreme heterogeneity of this population, and probably are a valid reflector of the wide heterogeneity of the population of blind children in general. We have seen how both biologic and social/environmental factors can have significant effects on the developmental progress of these blind RLF children. Further research is needed to more completely describe these processes.

Implications for Physicians

As physicians, we should heed the warning of Dr. William Silverman, who, in his book on RLF, described his conversations with mothers of now grown-up RLF adults:

"...once the diagnosis of RLF was made...at the very time [parents] needed support and advice, their physicians became distant and defensive... Most [parents] blamed their doctors for failing to maintain interest and concern, not for failure of clairvoyance. 11A

The message is clear. We, as ophthalmologists, pediatricians, family practitioners, and other professionals need to take a more active role in helping these children and their families. This can be accomplished by such means as: knowing about and referring to early intervention programs, providing emotional support for the child and family, helping the family integrate information from other professionals, encouraging parental advocacy for the child and referring¹⁵ parents to written books, pamphlets, and local and national advocacy organizations.

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PERINATAL CHARACTERISTICS OF BLIND CHILDREN (RLF)

CASE #	Year of Birth	B.W.(grams)	G.A. (weeks) (*: SGA)	Sex	Race	Days in Hospital (+18)	Days on Oxygen	Appears @ 1.5 min.	Perinatal Complications (All had RDS, BPD)
1	1978	990	30 (*)	M	W	75 (+18)		7,9	placental abruption; prolapsed cord; c-section; hypotension; ? sepsis; pneumonia; PDA; apnea; transient diabetes.
2	1978	710	26	F	non-W	144	135	1.5	P.R.O.M.: PDA, hyperbili.(10.3) requiring one exchange tx; sepsis x 2; hydroceph. (shunt); abn. EEG; rickets.
3	1978	1470	29	M	W	104	97	4.6	vaginal bleeding before/after amnio; stat c-section; birth asphyxia; apnea; hyperbili. requiring one exchange tx; IVH (grade V); hydroceph. (shunt); PDA.
4	1979	1380	30	F	W	89	74	8,10	elective c-section for Rh hydrops; hyperbili. (15.4) requiring six exchange tx; PDA (Indocin).
5	1979	930	27	M	W	135	131	1,4	cord prolapse; c-section; bruising; apnea; hyperbili. (12.8) requiring 13 exchange tx; (ligation); rickets.
6	1979	980	29	M	non-W	77	77	4,6	Twin A, (Twin B died); PDA (Indocin); CHF; hyperal. hepatotoxicity; sepsis; hyperbili. (8); apnea.

Figure 1

PERINATAL CHARACTERISTICS (continued)

CASE #	Year of Birth	B.W.(grams)	G.A. (weeks) (*: SGA)	Sex	Race	Days in Hospital	Oxygen	Apgars @ 1,5 min.	Perinatal Complications (All had RDS, BPD)
7	1980	800	27	M	W	180 (+ 150)	540	Home	? placental abruption; asphyxia; FTT; pseudomonas pneumonia; IVH (grade VI); PDA (ligation).
8	1980	1370	31	F	W	89	80	2,6	maternal diabetes & severe pre-eclampsia; late decelerations on OCT; stat c-section; hypotension; PDA (ligation); apnea.
9	1982	670	26(*)	M	non-W	172	125	2,5	P.R.O.M.; maternal infection; apnea; PDA (Indocin); seizures; ? meningitis; brain infarction & hydrocephalus; absent suck.
10	1982	700	28(*)	F	non-W	120	120	Home	asphyxia; cor pulmonale; CMV (congenital vs. acquired); apnea.

Figure 2

VISION & DEVELOPMENTAL FOLLOW-UP
BLIND CHILDREN (RLF)

CASE #	AGE * @ LAST EVAL.	VISION	ADDITIONAL HANDICAPS & PROBLEMS	RELATIVE STRENGTHS
1	4-4	None	-severe language impairment -autistic-like behavior -aggressive	-orientation/mobility -improved behavior
2	2-6	? Light Perception	-language delay -no self-feeding	-orientation/mobility
3	3-5	None	-spastic C.P. tactile defense. -severe M.R. -lack of chewing -irritability, crying	-response to affection
4	3-2	Light Perception	-rote language (mild)	-orientation/mobility -self-help
5	3-4	None	-delayed gross-motor -rote language -poor socialization -significant self-stim.	-very responsive to music -receptive vocabulary

VISION & DEVELOPMENTAL FOLLOW-UP
BLIND CHILDREN (RLF) (cont.)

CASE #	AGE * @ LAST EVAL.	VISION	ADDITIONAL HANDICAPS & PROBLEMS	RELATIVE STRENGTHS
6	2-0	None	-macrocephaly -language delays	-walking well -self-help skills
7	2-2	None	-chronic lung disease, fatigue -chronic undernutrition -functional M.R.	-responsive to affection
8	2-3	None	-afraid to explore unfamiliar environment	-verbal -self-help skills
9	11 mon.	None	-spastic C.P. -severe M.R. -fed by tube	-recognizes mother's voice
10	10 mo.	Light Perception	-? delayed language	-exploration of objects -responsive to affection

*Age adjusted for prematurity

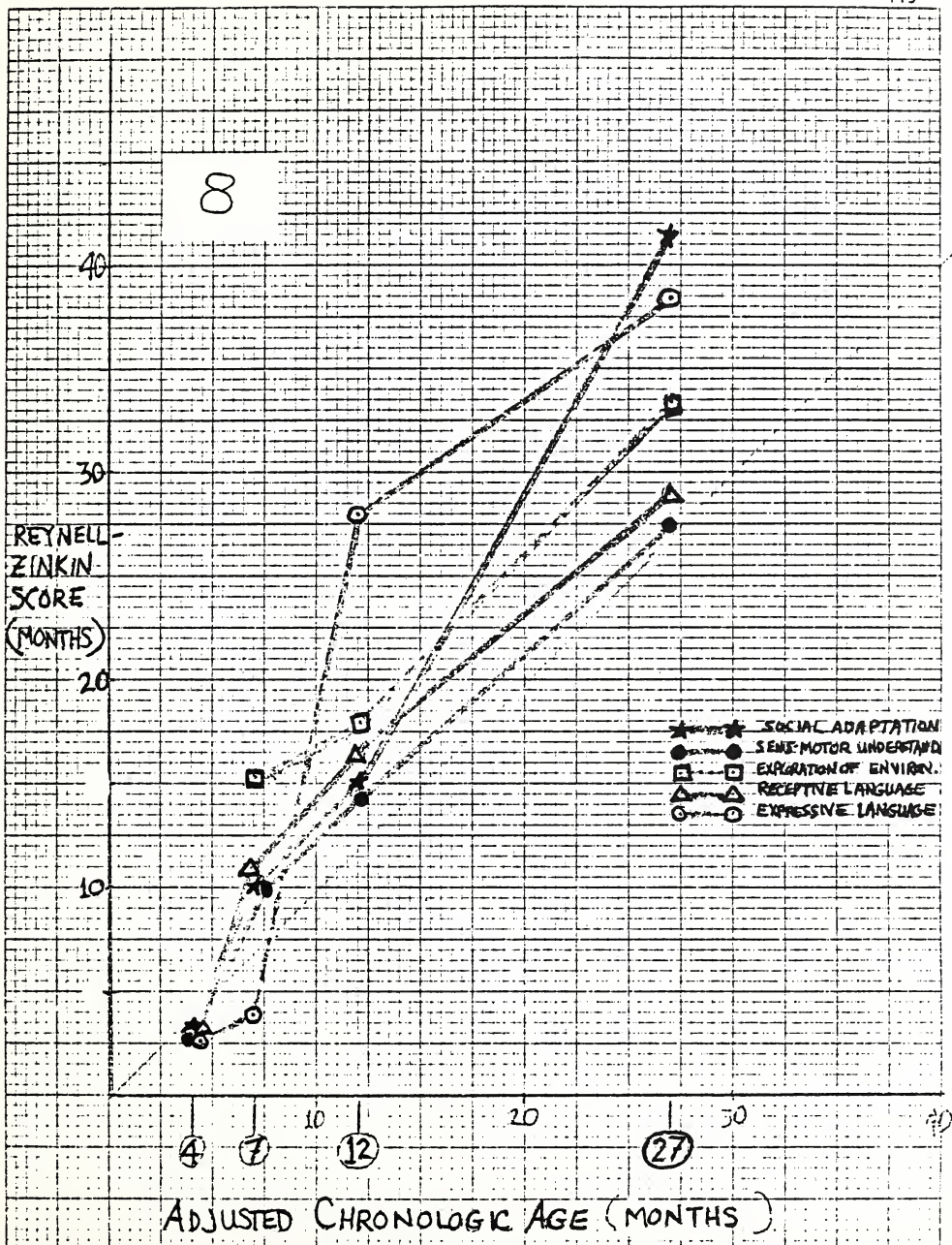
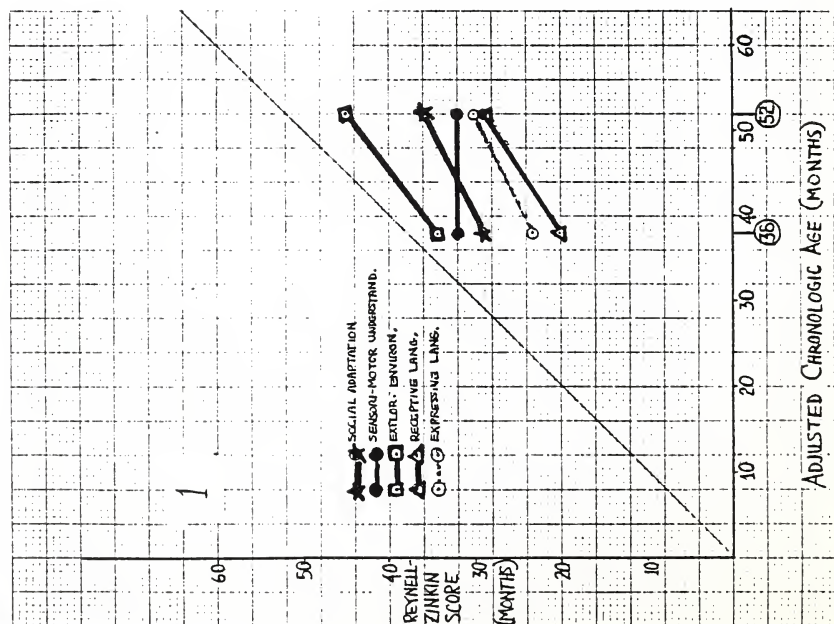


Figure 5

A



B

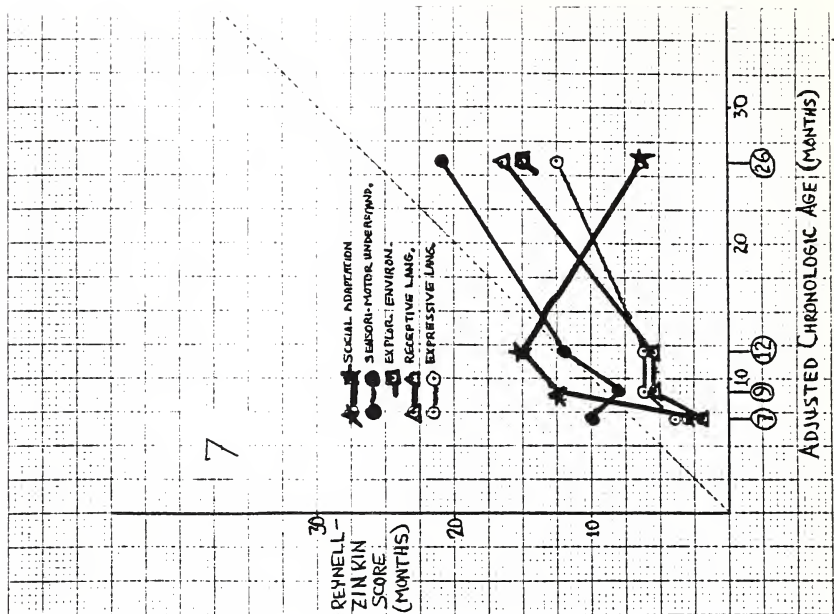


Figure 6

PEDAGOGICAL METHODS AND MATERIALS HELPING

SEVERELY MULTIHANDICAPPED BLIND CHILDREN TO DEVELOP

Lilli Nielsen
(Denmark)

In the last 15 years we have in Denmark tried to design pedagogical methods and materials for blind children who are mentally retarded and functioning at a low level.

To do this we have found that it is necessary to observe the way in which each child is able to use those senses which are functioning. To enable us to make a good pedagogical program for a child we at first observe very closely in what ways the child is listening and touching, what sort of smells and tastes the child prefers and in what ways the child moves. We try to find out which movements can be defined as kinesthetic, or conscious, and which movements are not yet kinesthetic and therefore can be defined as unconscious.

In my opinion the kinesthetic sense is the most important sense of all. None of us can use our other senses without using the kinesthetic.

From knowledge about how the child is using his senses, and not the least from knowledge about the very small steps in normal development, we can arrange several surroundings for the blind multihandicapped child so that he can have the best opportunity for development.

There are two parts which make up the contents of the program. The first is for us to make a decision about the different surroundings we will offer the child during the day so that the child, by self activities, can develop an interest in relation to the outside world. Blind children in the first years of life and mentally retarded children at a low functional level can only learn to understand about the outside world thru interaction within their own activities. The adult can inform the child about the surroundings and in this way perhaps get the child interested. But the child can only understand by having an awareness what he himself is experiencing.

In the second part of the pedagogical program we will make a decision about which play or activity the adult, now and then, shall do with the child. We are never training our children, we are interacting with them. For example: by offering them toys for mouth-motoric play so that they can be better eat solid food, babble and perhaps talk - or by building towers they can overturn - or by setting objects in boxes that the child can empty - or putting together toys which the child can take apart - or by talking about and showing an interest in what the child is doing.

We are never guiding their hands all the time because we are aware that the child may learn that he will be active only when an adult is guiding his hand.

Many of our blind multihandicapped children have to have special materials if they are to be sufficiently motivated for activity.

The Resonance Platform

The resonance platform is designed to give the child a reinforced stimulation every time the child moves. In the beginning we introduce the resonance platform to the child. This means that the adult seats herself upon the platform with the child in her arms, making some sounds upon the platform and slowly placing the child in a sitting or lying down position directly upon the platform. Then she places a lot of toys and materials around the child's body, under his feet, his hands and perhaps his head. Then every time the child makes a movement, conscious or not, he will get in contact with something with which he will produce

a sound and because of the plywood platform this sound will stay as long as the child is aware of the sound and can be motivated to act again.

Before telling you about other materials I should like to tell you about an investigation which was done by Sven-Inge Windal in Sweden. He had heard about the resonance platform and he wanted to know if it was true that a child would be more active when placed upon the platform than when placed upon traditional mattresses.

A blind mentally retarded child who was not able to sit without support was placed upon the platform for 5 minutes and then placed 5 minutes upon a mattress - again 5 minutes upon the platform and again 5 minutes upon the mattress.

Sven-Inge Windal continued the movements of the child with the following result:

	<u>Head Movements</u>	<u>Leg Movements</u>	<u>Body Movements</u>
Platform	18	9	6
Mattress	0	1	1
Platform	10	11	2
Mattress	1	0	0

The platform is made of 4 m/m plywood measuring 1.50 x 1.50 m. On the one side of the platform is fastened a lift of 2 x 2 cm.

Vibrating Objects

Many blind mentally retarded children do not use their hands to grasp objects. Some of them because they cannot tighten their hands around an object and some of them because their hands, from spastic conditions, are tightened all the time. When we began to place a vibrating electric toothbrush or manicure apparatus in their hands, they began to tighten and loosen their fingers and to move the hand with the vibrating object against the materials around them. In this way they learn to use their hands in grasping ways.

The Bucket and the Activity-belt

Many of our blind mentally retarded children have difficulties attaining the ability of head control. One of the reasons for this is that they do not take both hands to the midline of their body. You will nearly always see that the blind mentally retarded are sitting or lying with their hands placed to each side of their body. To motivate them to move their hands toward the midline of their body we give them several special activities. With the bottom up we hang a bucket over the head of the child who is lying on his back upon the resonance platform. When the child is breathing and babbling, or perhaps crying, he will get an echo-answer from the bucket and he will get a response from the bucket that he is able to reach and touch from the midline of his body. This has helped some of our children to begin to move their hands against the bucket and to move their hands together. In that way they get the same basic condition for head control as seeing children. But we have also given our multihandicapped children something we call an activity-belt - a sort of bib upon which is fastened several metal links, strings of pearls, wooden bits and so on. With this it can be meaningful for the child to move his hands to the midline of his body and to play with the objects on the bib.

We also offer this activity-bib to the child who is always biting his hand or pinching his ear or has some other sort of stereotyped behavior. With the activity-bib they have the possibility to keep their hands occupied without

destroying themselves. I think that blind persons have a need for occupying their hands as seeing persons have a need for occupying the eyes.

Two years ago a department of the Swedish government offered some money to design prototypes of some new materials. Three of these materials are named "The Support Bench", "The Sound Box" and "The Little Room".

The Support Bench

Some children develop very slowly and this means that the body is growing whereby it is difficult for the child to go through that stage of development which would help him to sit without support. Normal children will, in prone position, at the age of 6-8 months, develop the ability to move arms and legs in a coordinated way. This activity will change the form of the spine so that the child gains the ability to sit without support.

To give the child who has developed to the stage of 6-8 months but at the same time is 4, 8, 10 or even 17 years old the possibility to go through this stage we place the child in prone position upon the support bench. Then the child can begin to move the arms and legs and will be motivated to activity if we place a lot of materials near his hands and feet for him to encounter.

The Sound Box

The sound box is designed so that the child, by placing just a hand or foot upon the top of the box, can make the tape-recorder play and of course can also stop the tape-recorder by moving the hand away.

Even the child who is so handicapped that he can do almost nothing, is able, with this material, to experience that he is the one who decides if the tape-recorder shall play or not and he can decide for how long a time the tape-recorder shall play. By being the person who can decide something, and by experimenting with time-condition, the child will gain small steps for development of his I-identity.

It is a good idea to make tapes of events from the child's own life. When listening to such tapes the child, little by little, will better be able to imagine and to remember - two abilities which also will help him to form his I-identity.

The Little Room

The little room is designed to give the blind child the possibility to learn about space and to reach for objects.

Sighted children are reaching for objects when they are 3-4 months old while blind children very often are 10-12 months old before they achieve this ability.

Some blind children will, instead of reaching for objects, develop a stereotyped motoric behavior which is turned against their own body. It is therefore important to offer surroundings which can help the blind child to begin to reach for objects as early in his life as possible.

"The little room" can be built to a size which fits each individual child and to meet individual goals. If we have a blind child who has not yet begun to reach for objects, we will build the little room with equipment which enables the child to get in contact with the outside world with whatever little movements he has and we will try to find out which sort of qualities the child will prefer - which surfaces the child prefers to investigate, which sounds the child prefers in response to reaching behavior, and which smells the child prefers in the room just now.

When the child has been accustomed to investigate the walls and the ceiling of the little room we will begin to build the little room larger so that in this way the child will be motivated to move his whole body around in the room and perhaps move in and out the room and through all this gain experiences which in some way are similar to the experiences and understanding about space sighted children attain by building a lot of different caves or playhouses. Blind children are not able to build playhouses or to find small rooms under furniture or other cave-like circumstances as early in life as they have a need for them.

All the materials I have mentioned have been developed during my work with blind mentally retarded children but there is no doubt that most of these materials will also be good for blind children without other handicaps.

Anyhow, I believe they can help the blind child so they will not develop in wrong ways. By offering these materials we can perhaps avoid some of the autistic behavior we very often see in blind children.

Before finishing I should like to warn against the handicap I call "taught helplessness".

If you are training and training without giving the child the possibility to get certification by his own activity he will get the handicap of "taught helplessness". Taught helplessness is a very dangerous handicap. It prevents the child from being a person who can decide for himself. Round the world we have too many handicapped persons who have the handicap of taught helplessness and I think that we, in the future, shall do all we can to avoid it. To do this we need to learn much more about how to give handicapped children the best possibilities to develop. I think we are on the way but we have just begun and it will benefit us to use these resources as we continue.

SIBLING PARENTING - IS THIS PART OF THE ANSWER?

Susan Ruff
(U.S.A.)

My husband and I lived in West Africa in 1963 and 1964. Among our neighbors, there were two little boys. I can picture them now almost as clearly as I saw them every day 20 years ago. The older boy wore a little gray shirt, open in the front, and gray shorts. I remember dusty legs and bare feet, and the biggest smile you can imagine. And on his left hip, all day, every day, he carried his little brother. The older boy looked to be about 8 or 9, 10 at the most, and the baby was about a year and a half old. I have thought of them often, particularly after I became a mother myself, and tried to cook dinner with a daughter on my hip.

Now I would like to turn to another scene. Eye Care, Inc., does ophthalmological work in Haiti. Our first permanent clinic, and our operating suite, are on the grounds of a center for handicapped children in Port-au-Prince. The Center for Handicapped Children is built around a court-yard, and in the middle of the court-yard is a large, shaded, fenced area for the youngest children. Some are in portable cribs, some on the carpeting which is placed on the ground in that area every day. There are toys in evidence, and the babies are clean, and cleanly dressed, and well-fed. But many of them simply lie there, and it is one of the saddest sights I have ever seen. One doesn't have to know much about infant stimulation to know that something is missing. The women who care for these babies are gentle and caring, but strongly committed to the idea that a quiet baby is a good baby. Babies who cry are held and rocked, but no effort is made to engage the babies' interest in the toys, or in their surroundings. If they are blind, no effort is made to stimulate their other senses, to draw their hands to the bottle when they are being fed, for instance. They are very passive.

Let me paint a third picture. At each of the five Eye Care clinics in Haiti, patients wait to be seen by the ophthalmic assistant or the doctor. And a common sight, one you have undoubtedly seen many times, is this: a visibly pregnant woman will be waiting. She will have a baby of less than two in her arms or on her lap, and she will often have another child, a little older, at her knee.

These three vignettes are part of a pervasive reality: the older sibling who has full-time, or almost full-time, responsibility for a younger sibling; the infant who should be receiving various kinds of stimulation and is not; and the parent who is overburdened in various ways, and is unable to provide special attention to one of the children in the family.

There are other problems, as well. The most serious is probably the situation in which a blind child is hidden away, because of cultural stigma. Incidentally, our little neighbor in West Africa was not blind, and in fact, in over a year of living there I do not recall ever having seen anyone who was blind. It occurs to me now to wonder about this.

There are several reasons to think of using older children to identify and work with younger children.

First, the older children are accessible. Many of them are in school, but even those who are not are generally freer and more available than the parents in a community, who may be working at home or away from home to support their families.

Second, they are not as culturally bound. Speaking especially of the blind infant, an adult may believe that this infant has no potential for a full and productive life, and may have seen no examples in his or her lifetime that

would indicate otherwise. But the child is not so bound in by culture.

Third, when a child is born with an impairment, the parents are often profoundly depressed. While an older child in the family may share in this depression, it is not likely to be as deep, or as long-lasting. Combined with the fact of less rigid adherence to cultural mores, the child is capable of hope, where the parents may have none. Children in general are receptive to new ideas.

Fourth, most of the older children will be parents themselves, one day. The lessons they learn as youngsters, about child care, and about the special needs of a visually impaired infant or young child, will help them in their own lives when they are raising their own families.

I would like to tell you about a program which is already being tried in many parts of the world, the CHILD-to-child program. You may already be familiar with it. And while I am describing some of the activities of this program, I hope you will be thinking with me of possible ways to use their good ideas to meet the needs we all share, to reach visually impaired infants and children.

CHILD-to-child is an international program designed to teach and encourage older children to concern themselves with the health and general development of their younger brothers and sisters. It was originally envisioned as a series of simple preventive and curative activities which could be carried out at the primary school level. Activity sheets were prepared on a variety of topics, to be adapted locally as appropriate. They emphasize the importance of children working together to help each other, and the children learn through experience. Teachers, community health workers, nurses and other children act as teachers. Children who are not in school can be involved almost as easily as those who are.

One series of activities involves children with diarrhea. It is defined as too frequent, watery stools, and the danger of death from dehydration is explained. The activities start with a simple survey: children are asked to find out from their parents how many times during the last year their younger brothers or sisters had diarrhea. They make a combined chart, at school, showing, for each pre-schooler, the child's age; how he is fed (breast or bottle); how many times he had diarrhea in a specific period of time (which may be a year, but may be another measure of time like "since the fiesta", if people do not normally think in terms of years.) Finally, they include in their statistics how many children died from diarrhea.

Whereas it may be terribly hard for health workers to go from door to door making such a survey, how easy it can be simply to ask school children. And if we ask a group of adults whether they know of blind children in the community, they may not respond. If a teacher asks the same question in school, the answer is likely to be forthcoming.

The diarrhea activities continue with a simple explanation of dehydration and how it is detected. A little baby-like figure is made from a gourd, or even a tin can. A slice is cut off the top, a small hole is made near the bottom, with a plug; the gourd is filled to the brim with water. Then the children pull out the plug, and watch the cloth, which simulates the soft spot on a baby's head, sink in as the gourd empties. They learn - and remember, because they have seen - that a baby with a sunken soft spot is dehydrated. Other experiments teach them to recognize other signs of dehydration; absence of urine and tears, for example.

Another simple activity can demonstrate to the children what happens when a child becomes dehydrated. Two flowers can be picked and put into containers, one a container with water and one without, so the children can see the flower which is in the empty container wilt. It may not be medically accurate, but it is not wholly inaccurate, and it is a dramatic lesson to the children.

Children are then taught how to make a "special drink" to help prevent dehydration. The special drink is, of course, a tiny bit of salt, a little sugar, and water, in very specific proportions. It is up to the local teacher to decide whether the children should be taught to mix these using measuring spoons, or a pinch of salt and a little sugar in the palm, but they are instructed to taste the mixture each time to make sure that it is no saltier than tears, and they are told that the child with diarrhea should be given this drink each time he has a watery stool. The children also learn that people, young or old, with diarrhea should eat as soon as they are able, and that babies being breast fed should continue to be fed and also receive the special drink.

Obviously, children may be learning things which their parents consider wrong. The diarrhea activities are a good example, because in many parts of the world it is believed that a person with diarrhea should be given nothing to eat or drink, and the children are learning exactly the opposite. There is no easy solution to this problem, but CHILD-to-child program developers have recognized that community acceptance of, and involvement in, the program is important. The children may be able to put on skits for the parents, to share what they have learned, and other joint activities can be beneficial.

CHILD-to-child activities in other areas are a bit more relevant to our concerns. One activity is called "understanding children with special problems", and encourages discussion about children they know with special problems: for example, 'why can't this child do everything the same as you can'; 'is the child to blame'; 'how do other children treat this child' and 'how would you feel if you had a problem similar to this child's?' The activities include simulating impairments; for example, simulating lameness by tying a board to one leg, and then letting the child attempt to take part in games. In general, however, the "activities" under this heading are confined to discussions, rather than the dramatic kinds of experiments devised to teach about dehydration.

Turning again to the question of visually impaired children, can older siblings help?

Certainly they can help to identify impairments. Children can be taught to look for signs of eye problems, to make and use simple E charts for testing vision. They can be made aware that some people see much better than others in the dark, and that a child who stumbles in the dark may do so because of a genuine ophthalmological problem. They can learn that eating yellow and green vegetables and fruits helps protect vision, and they can learn the importance of cleanliness and keeping flies off the eyes.

It is also possible to let children play with blind-folds, and experience not-seeing for a few minutes at a time. But I do not think they can grasp what it must be like to be blind from birth.

Selma Fraiberg, in *Insights from the Blind*, talks about the adaptive feat accomplished by a blind baby in coming to grips with the world, in developing concepts of self and otherness, of continuity in space and time. She points out vividly how much our eyes contribute to our early education, and how the blind baby can exist in a void, can be completely alone even when the mother is present, unless the mother is actually touching and talking to the baby. Children can, I think, be made to understand how important it is to hold, touch, and talk to a visually impaired infant.

Children can also be made to appreciate how important the blind child's hands will become, as primary perceptual organs. Simple activities can include trying to identify similar objects, by touch, when the objects are hidden in a bag, for instance. The objects could include small flat stones, coins, buttons, and so forth. It should be possible to move from this kind of experience to the suggestion that a blind youngster must be helped to touch many different kinds of objects, as long as they are safe to touch, and must be helped to explore the world.

Similar kinds of games can sensitize the children in other ways. For instance, trying to identify persons or sounds by ear alone, or learning to hear when a container held under running water was full. You can think of many other examples of activities which will dramatize for young children another child's special situation.

Finally, I think it is possible for children who empathize to learn not to be cruel, but equally important, to learn not to be too kind. That is, they can appreciate, perhaps better than adults, how much it means to accomplish something on one's own, and, with empathy and understanding, they can encourage a younger, visually impaired sibling to achieve mobility and independence - if they believe it is possible.

Parenting courses are increasingly important in the United States, at the junior high and high school level. Some seem to focus mainly on how to balance a check-book, but others teach the rudiments of child development, recognizing, as I think we must, that when a young person is already a parent that person has already taken on a huge commitment in terms of time and energy, and may not feel that there is time for the theoretical. Parenting, sibling parenting, as I have called it, is equally relevant elsewhere because of its immediate impact on children who already have responsibility for younger children. At the same time, it can be exciting, fun, and for many children, their first experience with a school topic that is actually relevant to their lives. As CHILD-to-child has recognized, it cannot occur in a vacuum, but must be part of the whole community health picture. The adults must be co-opted, made to feel a part of the effort.

I am here at this conference to learn, not to presume to teach any of you, because most of you have a great deal more experience than I have. So I would value your reactions to this idea of using the older sibling as a resource. Are any of you already doing this? Do you think it is worth trying? CHILD-to-child welcomes the idea of our adding activity sheets to the ones they have already compiled. So far they have involved over 1 and $\frac{1}{2}$ million children in almost 50 countries. They are a willing network for us to use to disseminate our ideas about what we would like children, and by extension, their families, to know. Can we spend the next little while in discussion?

YOUNG BLIND CHILDREN:

RESOURCE MATERIALS FOR WORKERS IN DEVELOPING COUNTRIES

Iain F.W.K. Davidson - Joyce Nesker Simmons
(Canada)

Resource Kit: An Invitation

For over a decade, Iain F.W.K. Davidson and Joyce Nesker Simmons have been working in the field of young blind children. Their earliest long-term project resulted in experimental assessment scales and A Handbook for Parents of Pre-School Blind Children. Currently they are producing a series of conceptual articles on various aspects of the impact of blindness on young children's development.

Their applied and academic emphases have led Dr. Davidson and Dr. Simmons to begin writing resource materials for workers with young blind children in developing countries. Consultation and correspondence with professionals in every continent over the last year have assisted them in drafting basic materials which are summarized in the accompanying outline.

The preliminary stage has made the authors very aware of the need for continuous dialogue with the potential users of the resource materials. Questions of format, level, content, illustration and medium still remain. For example: Do different types of workers require different types of presentation? Do you prefer loose-leaf or bound material? What level of detail is appropriate for different settings?

Although Dr. Simmons is not able to attend the conference, Dr. Davidson is present, and eager for questions and general feedback regarding the resource kit. By the end of the conference, he is hoping to have reached as wide an audience as possible in order to arrange for further development of the resource materials and for their field testing. Please try to contact Dr. Davidson during the conference. Above all, please complete the attached questionnaire.

Your input will enable the authors to proceed with confidence.

Outline of Resource Materials

Purpose: To provide guidelines and materials for use with a wide range of workers with young blind children and their parents.

Materials:

A. Rationale

There is a shortage of materials for guiding the development of young blind children. Using non-specialized materials with these children fails to take account of their unique developmental mode. Since the impact of early blindness is global and pervasive, we are selecting materials to fit a conceptualization of the development of young blind children as specialized.

B. Content

1. Table of Contents

Chapter 1: Impact of Blindness on Child's Development and on Families:
Blindness: Causes, Types, Degrees; Attitudes to Blindness; Unique Developmental Mode, Multi-handicap.

Chapter 11: Assessment: Identification of Blindness; Determining Developmental Levels; Types of Ability and Needs; Assessment Processes; Checklists.

Chapter 111: Guiding Parents: The Role of the Field Worker; The Role of the Parent; Guide to Finding & Using Community Resources; Finding Materials; Auxiliary Care & Advice.

Chapter IV: Practical Suggestions: Physical Development & Mobility; Language Development; Intellectual Development; Social Development; Emotional Development; Self Care; Play; Mannerisms; Developing Use of Vision.

2. Style of Presentation

All information will be supplemented by:

- Miniature case studies or vignettes;
- Focussed question & answer sections;
- Procedures for reviewing the success or failure of suggestions, techniques or general developmental objectives.

C. Guidelines (i.e. How to Use Materials)

Young blind children follow a unique developmental route which is described in detail in the resource materials. Effective intervention requires a thorough appreciation of that uniqueness. Guidelines for providing appropriate intervention to match needs are given in a detailed discussion of mediation.

No set of resource materials can be too specific. Each programme or item of advice can only be created in the light of such factors as the child's developmental level and needs, the family's capacities and circumstances and the field worker's experience. Therefore, we are providing basic information and generic guidelines to assist the field worker in making decisions about specific children and their families.

Range of Use:

A. Field Workers

The three groups of field workers identified to date are:

1. Professional Worker (Education and/or training in their field, e.g., medical doctor, psychologist, social worker, teacher-trainer);
2. Trained worker (adequate literacy and/or basic training, e.g. assistant nurse, elementary teacher);
3. Aide (minimum literacy and/or simple apprenticeship).

B. Parents

Materials available as designated by field workers.

C. Settings

Materials are supplementary to demonstration and teaching, also may be associated with wide range of audio-visual aides.

Planning and Reviewing

To enable field workers to maintain quality control, we intend to provide practical methods of keeping track, such as check-lists and review sheets.

Keeping track of the progress of children and of their parents is vital. While the practical difficulties are many -- huge case loads, suspicious or fearful parents, maintaining files in unfavourable conditions, the effectiveness of field work depends on the ability to plan and review.

COMPUTERS: A TOUCHY TOPIC FOR HANDICAPPED AND NONHANDICAPPED LEARNERS -
I.C.E., INC.

Jan Battenberg - Hallie Overman
 (U.S.A.)

In the classroom of 1983 the gifted child is learning to write a computer program, another child works to become computer literate. Through the efforts of Instructional Computer Equipment, Inc., the special education child, as well as the nonhandicapped, will benefit from computer technology.

Once limited to use as drill, repetition, or game, the computer is being challenged by I.C.E., Inc. to meet the individual learning styles of both regular and special education students. I.C.E., Inc. has developed computer software and hardware peripherals which, when combined, facilitate learning through individualized programs utilizing a child's unique learning style, needs and learning strengths.

I.C.E., Inc. stresses curriculum to a greater degree than computer hardware in its evolvement of computer assisted instruction and computer managed instruction. I.C.E., Inc. developers feel the importance of maximizing curricular capabilities has been overlooked because of mechanical limitations of the computer. While other companies are selecting hardware for writing courseware (instructional software), I.C.E., Inc. has reversed the process in first creating instructional curriculum which adapts to a child's unique learning needs and styles, operationally defining the curriculum for courseware, then modifying existing hardware to accommodate the instructional format.

I.C.E., Inc. developers have found computer assisted instruction can go far beyond drill, repetition, or simply tutorial reinforcement. The conversion of curriculum through the I.C.E., Inc. system to courseware via the touch-sensitive and audio computer provides a teaching machine rather than mere drill and repetition. The computer allows for alterations for various individual student performances as established through criterion-referenced assessments and baseline data. Computer managed instruction will also be available for student record keeping and management control.

The I.C.E., Inc. system offers the learner the opportunity to selectively attend to the instructional material by providing for individual processing of information which adjusts to individual learning styles of varying degrees of ability areas and levels of sequential skills. Inability to utilize, overall difficulty, or confusion which may occur in the learner's usage of a computer keyboard will be removed and simplified by merely touching the screen for an appropriate response. Should paper-pencil follow-up or additional practice be warranted, the optional usage of a printer will be made available as a peripheral hook-up.

I.C.E., Inc.'s computerized system is supported by psychological and educational research. The curriculum is based on fourteen years of applied research within various educational settings: public and private, group and individual instruction, graded and non-graded, handicapped and non-handicapped. The curriculum has been researched in preschools, elementary and secondary schools, and at the university level. Based on documented research, the curriculum content stresses the need to meet the learner's individualized learning needs through an approach that includes remedial, developmental, and compensational techniques. The student's abilities, strengths and weaknesses, skill levels, behavioral and motivational needs are given consideration by I.C.E., Inc., as well as convenience of usage by both student and teacher. One of the major goals of I.C.E., Inc. is to allow ease in interfacing both student and computer and/or teacher and computer.

FIRST STEPS - PARENTING, PREVENTION AND PROGRAMMING

Heather Hewitt
(Australia)

First Steps - Parenting, Prevention and Programming as a theme for this seminar, captures the essence of the occasion. We are gathered here in the interests of visually impaired children the world over. We are drawn from many parts of the world, and represent many cultures. Nevertheless we share much common ground. Basically we are all subject to the same formative processes. We all gained our first learnings in a familial context and at the hands of our parents. Elementary perhaps, but fundamental. I urge you not to lose sight of this fact as we discuss Early Intervention Programs for Visually Impaired Children.

Early Intervention is a fundamental need. However it is the prerogative of the home and the family, not the formal educative system, for in all countries, in every culture, the centre for all learning for the young infant is the home, and his parents his first informal teachers. So it must be for the visually impaired child. It is regrettable that a truth so obvious, is so frequently overlooked by professionals when devising programs aimed at assisting visually impaired children take their first steps.

In developed countries these programs tend to be dominated by sophisticated interprofessional teaming by highly trained staff, complex assessment schedules, individual programs for children, supported by a wealth of audio-visual material.

In developing countries, where intervention programs are often just emerging, the financial costs involved in establishing similar programs can be prohibitive.

International conferences however, provide an opportunity for people from all parts of the world to come together to talk, discuss, learn from each other, and hopefully share solutions to their problems.

Aubrey Webson in his excellent opening address issued us with a challenge. That challenge was for us, here at this conference, to face the harsh realities that confront many developing countries trying to provide early intervention services for young visually impaired children. Mr. Webson defined these harsh realities as poverty, ignorance, and inadequate social services. He left us with the question - where do such countries start?

In my paper today I will try to respond to Mr. Webson's plea for that is the purpose of these conferences - to share our problems and suggest possible solutions. While I do not pretend to have all the answers to this very valid question, I have always found it useful that when faced with what can seem an insurmountable problem to take the first step of identifying and isolating the essential components that have to be dealt with. To separate the wood from the trees, as we say in our country.

With this in mind, I would like to take this opportunity to identify what I consider to be the essential truths of early intervention in all cultures. In this I have two aims:

Firstly, to enable developing countries to identify some of the options of parenting, programming, and prevention readily available to them. Options which do not entail huge financial burdens and sophisticated professional resources.

Secondly, to enable developed countries to use these essential truths as a basis for evaluating their programs. To ensure that in the process of refining and making their programs more professionally sophisticated, these essential truths have not been lost.

With these two aims in mind, let us now examine what I consider to be the essential truths in early intervention programs in all cultures.

The first truth is that early intervention programs, aimed at assisting parents to teach their handicapped pre-school child basic survival skills, are not educational options, nor necessarily expensive.

They are not a luxury, an educational frill attached to a well developed educative system. They are an essential part of any responsive educative system. The reason being that the success of later educational programs (be they segregated or integrated into main stream schooling) depends heavily on the success parents have had in preparing their child for school.

Let us take the case of an intelligent visually impaired infant. If the parents are so alarmed by the magnitude of the parenting task ahead of them that they feel unable to respond naturally to their baby, their child suffers enormously. Left alone, unstimulated in his cot, experiencing little human warmth and contact, he will surely be at risk. By school age he may well have become developmentally delayed, unable to use his residual vision effectively, and show signs of emotional disturbance. From being a visually impaired child with good educational potential, he has developed into a multi-handicapped blind child. Such a child may not readily benefit from school programs available. However it is just such a child who benefits most from early intervention programs. Two centuries ago Jacques Rousseau, the famous philosopher, appreciated the truth that a child's education begins at birth. Our task as educators is to ensure educational intervention commences at the earliest possible point - at birth. In both developed and developing countries early intervention must be our first educational priority if visually impaired children are to achieve their full educational potential.

It is also important to appreciate that the longer educational intervention is delayed, the more expensive subsequent educational programs become. Special education requiring segregated provisions and highly specialized support systems (as do many programs for the multi-handicapped) is a much greater financial burden for a community than main stream or integrated education. The more successful early intervention is, the more likely it is that a disabled child will benefit from regular mainstream schooling. Thus, where there is only limited financial resources for education, it is sound financial policy, and good educational practice, to reserve part of these funds for early intervention programs.

The second truth is that highly trained personnel and sophisticated resources are not essential for effective programs.

While these certainly assist in establishing services in a minimum of time, perhaps more than in any other area of education, successful early intervention programs may be mounted with a minimum of professional staff and sophisticated resources.

In devising programs we must not lose sight of the essential truth that in every culture it is the parents who teach their child to walk, to talk, to develop basic self care skills, to make friends, to become acceptable contributing members of the family and community. So it must be for the visually impaired child. The aim of the intervention program must be to teach the parents, not the infants. To assist the natural parents modify the traditional child rearing skills already so familiar to them in order that they might effectively meet the special needs of their visually impaired child, not to provide an array of highly trained specialists to teach the young handicapped child.

The role of assisting parents with their parenting can be a most difficult role for some professionals. In my unit in Australia we had a most comprehensive array of professionals - psychologists, speech therapists, welfare officers, special teachers, social workers and so on. However I do not believe such resources are essential to facilitate effective parenting. Too often the

intervention sessions were spent with the professionals teaching the child, while the parents sat passively observing, learning little about parenting a visually impaired child, and frequently losing confidence in their parenting, as they watched the professionals taking over their rightful role. To sit back and observe parents interacting with their children, and only intervene by suggesting ways they might get a more rewarding response from their visually impaired child, is often a more difficult role for professionals than it is for volunteer parents. It requires not only a sensitivity to parents who may have a different socio-economic and/or ethnic background to oneself and therefore have perhaps some differing views on child rearing. A sensitivity which enables one to respect and build on that particular parent's mothering skills rather than attempting to change it by imposing one's own values associated with child rearing. It also requires a confidence in oneself as a person, so that never is the session at risk of being used to demonstrate how competent the professional is. That one happens to be a qualified member of a profession does not necessarily mean that one possesses those personal characteristics so essential for effective intervention. Many volunteers, however, do possess these essential qualities if you are prepared to look for them.

The aim of intervention in the young infant is to facilitate the natural parenting, not to make parents professional teachers, or to have professionals teach young infants.

Developed countries must heed this truth and when assessing their programs ask the question - are their professional staff facilitating parents, or are they taking over the role of parents and teaching young infants.

Developing countries must also heed this truth. Resist the temptation to follow the western model of using limited professional staff to conduct programs. Rather use them to train and supervise the natural human resources available to you. The hundreds of volunteer parents who already have a wealth of knowledge of the child rearing practices of their particular culture, on which you can build programs. Volunteer parents only need to be taught ways of modifying these time honoured traditions and customs to meet the special needs of the visually impaired child. Once equipped with this knowledge and a basket of toys traditionally used by parents of their culture, they are ready to go to work. To support and demonstrate to the natural parent, the most effective and rewarding ways of meeting the social, emotional and educational needs of their children.

It has been my experience in developing countries, that local volunteer parents, once accepting the responsibility of contributing to intervention programs, show great ingenuity in devising ways of assisting the natural parents. This process also helps foster a sense of community concern for the handicapped and their families. As Susanna Crespo from Argentina said in her paper yesterday, it is not only the teacher who can be an educator as such. John Mann from Mississippi, U.S., also acknowledged the contribution volunteers can make to intervention programs in his paper yesterday.

The third truth is that it is not necessary to establish large institutions for training personnel.

Certainly it is more expedient, if such resources are available to train large numbers of salaried professionals who can then establish programs on a nationwide scale. However I doubt that this is either necessary or desirable when initially introducing a program into a culture. In developing countries where there may be only limited professional staff available and few training institutions, I would prefer to concentrate my initial efforts on establishing one exemplary program as a demonstration model. Large numbers of volunteers and professionals can then be trained on the job using the 'apprenticeship method'. By this means local people visit the 'working model', observe it in action, and then return to their own local area, to establish a similar program.

This method was used in Indonesia where I had the opportunity of

working with Helen Keller International and the International Council for the Education of the Blind as a consultant in establishing an intervention program for families of young blind children. Some of you saw some of that program last night in The New Miracle Worker. I supplemented this by writing a simple booklet on the local parenting practices modified to meet the needs of visually impaired persons. The text was written in Bahasa Indonesian, to be used by those volunteers who were able to read, and the local professionals. Hopefully this booklet, together with the demonstration program will provide sufficient stimulation for people from other areas to establish similar programs. I know Mr. Webson in his opening address expressed some valid concerns regarding the concept of model programs, but services in most countries usually grow from small beginnings from model programs.

The concept of a demonstration model can also be used by developed countries for purposes of evaluation. By centralizing a group of the most skilled professionals available in one exemplary program, professionals from regional programs can visit, receive ongoing inservice training, use the service as a consultative agency, and evaluate their own programs against this exemplary model.

The fourth truth is that expensive equipment is not essential for effective programming.

In Australia our unit had a magnificent toy lending library, holding specifically designed toys for visually impaired children, and an extensive reference and lending library for parent use. Each parent was provided with a cassette recorder and taped material including a taping of each session so that family members who could not attend the session could participate in the program. Children's progress was videotaped and extensive use made of videotaping for assessment purposes. However I do not believe such sophisticated resources are necessary to facilitate effective parenting. In fact, I think that too often they inhibited the natural parenting. Often the elaborate toys tended to dominate the parent-child interaction, and some parents forgot how to play naturally with their children.

I found it most interesting, that in preparing the booklet for Indonesia, where I had to make a study of the toys, games and songs found in the poorest homes, almost all of them achieved the same effect as the elaborate toys and equipment in our own lending library. I believe the same would hold for all cultures. Facilitating parenting necessitates the use of traditional songs, games and toys found in every home and these come free.

The fifth truth is that any intervention program must be built on the traditional parenting practices already present in that country.

To introduce a foreign welfare structure, no matter how efficient it may seem, risks only limited acceptance by the local people. Often it achieves token acceptance only, and will disintegrate when those who established it leave. What is necessary is the sense of ownership among the people which enables them to accept the program as their own, and assume responsibility for its ongoing development. Wherever possible, it should slot into existing services. In fact I believe this is the vital element for any successful program. There is little value in attempting to transplant a successful overseas program to the local situation and expect it to prove successful. It rarely happens and it is more often an expensive mistake, as both Aubrey Webson from the West Indies and Susanna Crespo (Argentina) reminded us earlier.

This truth applies to both developed and developing countries. Programs must grow out of the culture and be appropriate to the socio-economic population they serve.

Thus, if I may recapitulate what I consider to be the essential truths of early intervention in any culture. Truths which developing countries should heed when evaluating established programs.

1. Early intervention is not an educational option. It is an essential component of any responsive educative system on which the success of all later special education depends.

2. Early intervention is not necessarily expensive. It is sound economics and good educational practice to reserve part of any available funding for intervention programs.

3. Highly trained personnel and sophisticated resources are not essential for effective programs. Where necessary volunteer parents working under supervision of professionals can conduct effective programs, for the prime objective is to facilitate parenting, not have professionals teach young children.

4. Large institutions for training professionals are not necessary. Apprenticeship training in a demonstration model program can be used for duplicating new programs and evaluating established programs.

5. Expensive equipment is not necessary. The local traditional games, songs and toys familiar to all parents are the most natural means of facilitating parenting and should be the basis of any developmental program.

Given these essential truths, valid for all programs in all cultures, what information needs to be conveyed to the volunteer parents and/or professionals to enable them to assist the natural parents? While not negating their usefulness in effective programming, countries where developmental assessment schedules on which graded programs are based are not readily available, should not assume defeat.

I believe we can over assess children and over program parents to the point that the ultimate goal of facilitating parenting risks being lost. In our unit in Australia, once our array of professionals started working with a family even the family dog was lucky to escape assessment and programming. Stuart Teplin (North Carolina) also reminded us of the dangers of overstimulating children through intensive programming. Furthermore, while there is no doubt that an interprofessional team working together with visually impaired infants and their families can provide important data that can be used to design and conduct effective programs, believe me this does not come without its problems. In fact I believe these problems can be so enormous and complex that this is the reason that it rarely, if ever, is discussed at international conferences. I am currently involved in some research in this area and I would like to issue the challenge that those of us from developed countries who attend the next international symposium face up to the harsh realities that confront all interprofessional teams attempting to work harmoniously together in the process of team decision making related to parenting, programming, and prevention.

May I suggest that on this occasion we adjust our thinking to focus less on professional paraphernalia and more on human resources. We must then place our emphasis in better preparing these resources on behalf of our visually impaired children. To do this we must specify what are the basic modifications to traditional child rearing practices that volunteers and/or professionals need to be made aware of in order to assist the natural parents with their parenting role. The basic information is not great. The six main content areas are:

1. Parent Bonding

Volunteer parents are already familiar with the way emotional bonds are established between parents and children. They do not need an intensive series of lectures on child development to understand the warm protective feeling a baby arouses in his parents when, at about four months of age, the baby shows that he recognizes them as special, by smiling and wriggling when he sees them coming. What they do need to know is why the blind child does not react this way. That when they approach him he will not smile and wriggle, but rather remain very still, and that this is his way of trying to recognize who is coming. He is using his hearing to compensate for his poor vision. They can

then work out how to show the natural parent how to use tactile, visual, auditory, olfactory cues to help the baby identify each family member. With this simple information they will be able to effectively reassure the natural parents that their baby will eventually be able to recognize and show pleasure in their presence. They will be able to explain why this stage won't come until about ten months of age when all babies can associate sound with objects and therefore voices with people. Such simple knowledge can well give parents the reassurance they need to continue to show warmth and affection to what they may initially see as an unresponsive child, and so prevent the risk of the child becoming a disturbed multi-handicapped child.

2. Motor Development

Volunteer parents are already familiar with the traditional ways of teaching children of their cultures to sit up, to crawl, to walk. The only additional information they require is the role of vision in this process. That restricted vision means that the child will not be so motivated to sit up in order to see more, to crawl in order to reach things, to walk to imitate others. That this is the reason that many visually impaired children are slow to reach these milestones and not because they are necessarily mentally retarded. Given this simple explanation which they can convey to the natural parents they are readily able to encourage parents to continue to play the traditional games that parents in every culture play with their children and which serve to strengthen the muscles necessary for sitting, crawling, and walking. They can also demonstrate ways of using sound and touch and residual vision to encourage the child to sit up and crawl when he is ready, possibly somewhere around 10 months of age.

3. Educating the Hands

Volunteer parents can readily understand the importance of encouraging the natural parents to train their child to use their hands, as well as to use any residual vision he has, as means of gaining information. They will be able to support the natural parents in devising numerous games using sensory cues, to encourage the infant to reach out and grasp. Having listened to the paper of Vivian Correa's from Texas, I'm not going to say at what age this will begin. You can't beat an American for collecting scientific data to prove what thought was essential truth to be a myth.

4. Mobility and Orientation

Detailed lectures in body image, laterality, directionality, are not essential for volunteer parents already understand the importance of a child knowing his body and being able to move it confidently through space. They have already taught these skills to their own children through the traditional familial games found in all cultures.

Some basic information may need to be given on mobility training, such as keeping furniture arrangements stable, and simple travelling skills such as trailing and the correct method of using a guide, skills which are not difficult to teach volunteers.

Orientation skills are also simple to teach - the necessity of constantly talking to their child about where they are, and certainly there is no one better than the local volunteer to discuss with the natural parents the visual, tactile, olfactory and auditory cues in the village which can assist a blind child orientate himself.

5. Self Care

Again volunteer parents having had children of their own already know how to teach these basic skills - the only additional information they require are ways of using sensory cues to facilitate the child acquiring independent self care skills.

6. Self Stimulatory Habits

This is the one area that may be new to volunteer parents and some time will be needed to make them comfortable in accepting this behaviour. By self stimulatory habits I mean the tendency for children with impaired vision to indulge in habits such as eye gouging, head banging, rocking, filtering light, etc. Habits which often cause the natural parents great distress and frequently lead them to rejecting or believing the child is mentally retarded. Deliberate systematic distraction techniques are the most appropriate ways for parents to extinguish these habits. Volunteer parents, having reared their own pre-school children are already experts in the art of distraction and once understanding the reasons for self stimulatory behaviour they are well able to reassure parents and assist them with planned distraction techniques.

Thus it can be seen that all cultures, including those not yet dominated by technology, have sufficient resources to establish effective intervention programs.

The view I have offered to you this evening results from my own experiences working with handicapped infants in a sophisticated state wide service and in a developing country. I have emphasized the view that I do not believe we need massive material resources in order to make a significant contribution to the welfare of young visually impaired children. Indeed, I have stressed the human factors and the human heritage unique to each culture. While not acquainted with the many cultures represented among us, I am convinced that the fundamental value of this conference arises from the coming together of people from a variety of backgrounds and experiences. In wishing you well with your conference discussions I would strongly urge that the personal links you form throughout this conference are retained as an ongoing bond for the future. By maintaining communication and sharing our experiences beyond this particular occasion - The Second International Symposium for Visually Impaired Infants and Young Children - we have a rich human resource from which to draw upon in the future. I wish to thank the program committee for inviting me to be with you and to share some of my thoughts with you all. I thank you and wish you well.

PLAY BEHAVIOR AND LANGUAGE DEVELOPMENT

AS INDICATORS OF COGNITIVE DEVELOPMENT

IN YOUNG CHILDREN WITH LOW VISION:

The practical application of the results
from an exploratory research study.

Alice Sandra Parsons
(U.S.A.)

A child's world is a composite of many exciting people, things, and events. One favorite pastime is usually that of play. While playing, children of any culture find the freedom to express themselves through the objects they select and the activities in which they become involved. Many theorists tell us that learning can take place through play experiences and that these activities help the child to actively construct a knowledge base (Piaget, 1952). A young child's play behavior can provide information about the richness of the concepts that have been acquired and the experiential background of the child. Through observation of children at play with objects, one can derive much information about trends in their cognitive development as evidenced by increasing complexity of the activity across ages (McCall, 1974).

Play behavior has, therefore, been viewed as an easily implemented assessment technique (Ungerer, 1981). The appearance of the ability to use toys and objects in appropriate, adult-like ways has been considered a milestone in cognitive development. Kagan (1972), has suggested that an important cognitive change occurs during the first year of life in the appearance of the ability to create ideas about appropriate use of objects. Zelazo and Kearsley (1980) have studied infants and documented an orderly progression in the quality of play over ages. They stated that with increases in age, play becomes functional and appropriate.

Language has also been considered a reflection of what the child knows, and, therefore, an indicator of cognitive development (deVilliers, and deVilliers, 1979). Language provides a means for individuals to share thoughts, feelings, and ideas. Language is learned in a predictable sequential fashion, regardless of the culture or language acquired (Pollack & Halpern, 1971). Changes in language ability over ages provides evidence of the underlying concepts the child has acquired.

The child's ability to acquire information through sensory and motor experiences has been highlighted by many scholars as a critical factor in cognitive and language development (Piaget, 1952; Bruner, 1966). Play behavior provides a media through which one can learn much about a child's cognitive development, experiential background and ability to take in information through the senses. The presence of a visual impairment reduces the amount and clarity of information available to the child through the visual system. This deficit might result in effects on the play behavior of the child with low vision and interfere with learning that can take place through play.

The play behavior and language development of young children with low vision could provide abundant information about the children's ability to use distance vision in watching and learning about their world. The quality and quantity of their play behavior and language ability provides information about the amount of information they are acquiring.

This paper reports the results of a study on the play behavior and language development of young children with low vision. The purpose of the study was to gather information about the emerging patterns of play behavior and language ability of young children with low vision when compared to their normally sighted

peers, in order to gather information about the relationship of visual impairment to patterns of developing play behavior and language ability. The major questions of the study addressed the following issues:

1. The pattern of developing play behavior
2. The quality and quantity of play behavior
3. The relationship of the quality of play behavior to language ability
4. Possible differences between young children with low vision and their normally sighted age-mates on language ability as measured by the Preschool Language Scale (Zimmerman, Steiner, & Pond, 1979).

Subjects

The children included a group of 18 children with low vision between 2, 3, and 4 years of age. The children had no other diagnosed impairment and no diagnosed peripheral field loss. Their visual impairment was congenital and vision ranged between 10/100 and 10/400 as measured by the Flash Card Test for Children (Lighthouse Low Vision Services, 1970). A sample of 18 normally sighted children matched for age, sex, and ethnicity were included. Only those children considered to have intelligence within normal limits were included in the study. In each sample, there were six children in each of the three age groups including 2, 3, and 4 year old groups. There were 18 children in each sample for a total of 36 children in the study.

Instrumentation

Flash Card Test for Children. The Flash Card Test for Children (Lighthouse Low Vision Services, 1970) is a vision screening device widely used with young children. The symbols on the test are designed to be equivalent to the Snellen E acuities. Three figures, a house, an apple, and an umbrella, are presented in black bold-line drawings on reversible 4 inch by 5 inch cards. The test is to be given at 10 feet.

Play Behavior Protocol. The Play Behavior Protocol (Zelazo & Kearsley, 1980) was developed for the purpose of coding the play behavior of young children. The types of play behavior which are coded include the categories of functional, stereotypical, relational, and undifferentiated play behavior. The number of different ideas generated about appropriate uses of toys by the child is recorded. A set of previously defined adult-intended purposes is listed on the protocol for each of the six sets of toys. (See Table 1)

The Preschool Language Scale. The Preschool Language Scale (Zimmerman, Steiner, & Pond, 1979) is an evaluation and screening instrument that offers a detailed survey of the child's early language comprehension. The items on the scale consist of a series of auditory and verbal language tasks, each of which is assigned to a certain age level. Point scores and quotients are not to be equated with IQ scores or mental ages. Results yield information about the child's level of language development. Split-half reliability of the Preschool Language Scale corrected by the Spearman Brown formula yielded coefficients ranging from .75 to

Procedures

Each child was placed in an individualized, structured play session. A caretaker sat in a chair behind the child. The children were seated with six groups of toys placed in a semicircle in front of them. The toys included familiar objects found in many day-care and nursery schools in the U.S.A. (See Table 1). The children were allowed to play with toys independently. The play session was videotaped. The tapes were viewed later and each behavior was coded into four

categories of play. For the purposes of this paper, only two categories of play behavior will be discussed. They include the following:

Functional Play: Use of toys in an appropriate, adult-intended manner

Stereotypical Play: Mouthing, fingering, waving, and/or banging of a toy

Analysis of the Data

The video tapes were viewed and the play behaviors were coded. Inter-rater reliability was established through percent of agreement for every behavior that occurred. Reliability on every eighth case and on the last case included five inter-ratings and were 86%, 85%, 85%, 92%, and 92%, in agreement respectively. A phi coefficient was computed to determine the correlation between the coding of the two raters. All inter-ratings were significantly correlated ($p < .001$). All analyses were computed using various subprograms of SPSS, Statistical Package for the Social Sciences (Nie, Hull, Jenkins, Steinbrenner, & Bent, 1975). A one-way analysis of variance was employed to answer the majority of the questions of the study.

Results

The major findings of this study indicated the following:

1. The children with low vision spent significantly less time (a lower mean percent of the total behaviors coded) in functional use of toys ($p < .05$).

These results indicated that the presence of a vision impairment related to lower levels of functional play behavior. The children with low vision spent less time using toys in an appropriate manner.

2. The children with low vision spent a significantly higher percent of their play behavior engaged in stereotypical play ($p < .05$).

These results indicated that the presence of a visual impairment related to higher levels of stereotypical play behavior. The children with low vision spent more time mouthing, fingering waving, and banging the toys.

3. The children with low vision spent a significantly higher percent of their play behavior wandering away from the toys and the play session ($p < .05$).

Careful viewing of the video tapes indicated much of this behavior as aimed at interaction with the caretaker to get attention and to obtain one-to-one attention during the play session.

4. The children with low vision and the normally sighted children were similar in the total number of behaviors exhibited during the play session.

Both groups spent much time with the toys, and there was no significant difference between the samples of the total number of behaviors coded in actual interaction with the toys.

5. There was no significant difference between the low vision and normally sighted children in the number of different uses the children displayed while using the toys:

There were 36 appropriate uses coded (See Table I). There seemed to be a similar ability on the part of both samples to generate ideas as to the appropriate use of the toys. However, the children in the normally sighted sample were observed to spend much time repeating uses; the children with low vision did not appear to do this.

6. There was a significant and positive relationship between language ability as measured by the Preschool Language Scale (Zimmerman, Steiner, & Pond, 1979), and the quality of play behavior for children with low vision. Results of a Pearson Correlation revealed that these variables were significantly correlated ($p < .05$). The relationship was a bit stronger for the normally sighted children ($p < .01$).

Considering play behavior and language development as indicators of cognitive development, one might expect scores in these two ability areas to correlate. These results support this supposition.

7. There was a significant difference between the children with low vision and their normally sighted peers on the auditory comprehension quotient, and the verbal ability quotient of the $p < .001$, and $p < .001$ respectively.

These results indicated the children with low vision in this study were significantly lower in their language ability as measured by the Preschool Language Scale than their normally sighted peers.

Conclusions

The results indicated that there were significant differences between children with low vision and their normally sighted peers when compared on their play behavior and language development. These differences indicated a significant main effect of visual impairment on patterns of emerging play behavior and language ability in young children with low vision. These results suggest also that the visual impairment affects the child's ability to acquire the information necessary to develop concepts about their world which provide the foundations of language ability. These data indicated that experiential deprivation related to visual impairment is revealed in the patterns of play behavior of children with low vision. These children do generate ideas about the functional use of toys indicating the intactness of the cognitive structures necessary to this task. However, in relation to their normally sighted age-mates, they spend significantly more time in repetitious stereotypical behaviors.

These differences are significant when considering the importance of repeating functional uses of objects to learning. Piaget (1952) stated that each time a child repeats a task he varies it just enough for learning to take place. While these data indicated similar quality of play in the similar number of different appropriate uses of toys exhibited by each sample, the data indicated also a difference in quality related to extended engagement in the functional use of toys. Quantitative differences in the amount of time engaged in functional and stereotypical uses of toys on the part of the children with low vision when compared to their normally sighted peers indicates the need to actively teach young children with low vision functional play skills.

Recommendations

In any culture or community, the active interaction of the child with the people, objects and events in the surroundings are essential to normal growth and development. The findings of this study provide data to support the practices used by many professionals who are working with young children with visual impairment at home or in the early childhood program. Play activities are very important to the cognitive and language development of the child. A list of recommended practices to be used with young children with low vision to facilitate the development of functional play and learning through play are listed below. One cannot assume that children with low vision will acquire automatically the functional play skills they should have to render play activity a learning experience. Children with low vision should receive assistance and active instruction in the functional use of toys and objects within their environment. This effort can be combined with activities designed to increase their efficiency in use of low vision.

1. The child must be encouraged to use vision to explore the surroundings. Encourage the child to be conscious of how he or she is seeing. Parents and teachers must help the child develop efficiency in use of near and distance vision. With

efficiency in use of low vision, much information about the surroundings can then be incorporated into concepts and activities.

Developing near vision:

Encourage the child to:

- . examine closely the objects of play
- . look for prominent visual cues and characteristics
- . use these cues to correctly identify the objects
- . use native language to discuss what is being seen while looking carefully at objects

The adult can then:

- . monitor the concepts the child about the use of vision and how well things are seen
- . listen to the child's reactions to objects
- . obtain information about the accuracy of impressions on the part of the child
- . dialogue with the child provide much information about how well the child is using vision including:
 - . how things are perceived
 - . experiential background of the child
 - . concepts that have been acquired
 - . concepts that are lacking
 - . skills in the use of vision
 - . motivation to look and use vision
 - . efficiency in use of low vision

Developing distance vision

Encourage the child to:

- . view events and things at a distance
- . identify objects at a distance
- . locate, fixate upon, and move to objects in the distance
- . discuss the objects (people, trees, buildings, animals, etc.).

The adult can then:

- . ask the child probing questions about the experiences:
 - . what do you see?
 - . have you ever seen one before?
 - . what does it look like?
 - . tell me all about it!
 - . is it clear, do you need to move closer?
- . have the child watch the parent or teacher model action and movement, ask the child questions about what is seen:
 - . what am I doing?
 - . watch me!
 - . see how I do it?
 - . now you do it!
 - . show me!
- . teach the child the correct movement and position for the actions you are modeling
- . this can be done co-actively (place your hands and arms on the child and actively move the body parts through the motion)
- . always provide positive reinforcement and a great deal of praise

2. The child must be encouraged to acquire the native language in correct content, form, and use. The opportunity to participate in many experiences and develop many concepts will provide the content of language. Helping the child to pronounce words correctly and learn the shape and contour of the native language. Assisting the child to put words together in meaningful phrases will provide the correct use of language (Bloom & Lahey, 1978). Often, children with low vision

have good form and use, but lack in the content to give full meaning to their language.

Developing form and use of language:

The adult must:

- . always provide a good language model
- . make sure the child is listening to you
- . listen to the child's language for correct form and use
- . correct and shape the form and use of the child's language
- . include the child in dialogue
- . talk about daily routine at home while engaged in activities
- . discuss activities being done and their purpose
- . use correct language models constantly in all events
- . praise the child for correct form and use of language
- . be sure all family members discuss events, objects, and experiences with the child as they occur

Developing the content of language:

The adult must:

- . provide many experiences for the child
- . include the child in all activities and discuss these with the child
- . provide appropriate labels for objects while they are being used
- . help the child identify objects visually and label them correctly while using them
- . discuss events and experiences
- . help the child tie the correct language labels to the experiences and events
- . monitor the child's concepts as they are being formed by discussing events and activities
- . ask questions about the child's experiences while involved in these activities
- . encourage the use of appropriate language
- . introduce many new objects and experiences to the child
- . always insist the child use language to acquire what is desired

Through play activities the child must be actively taught the correct use of objects and the correct language labels for these objects and experiences. Through the above suggestions, one can assist the child in building and developing the use of appropriate language and in the acquisition of many concepts about the surroundings. A wide variety of objects and experiences familiar to the child's native environment must be actively introduced by the family members and caretakers. This will involve the child in the active process of growth and development and help to alleviate possible developmental delays related to experiential deprivation related to severe visual impairment. With the active interest of the parent and teacher in teaching the child play skills, learning through play and the development of language ability may be facilitated.

TABLE I

Toys Classified by Gender Category with 36 Appropriate Uses

Gender Category	Toys	Appropriate Uses
Neutral	Teapot, two cups, saucers, and spoons	Cover on pot Stir spoon in cup/pot Pour from pot to cup Drink from cup Drinking sounds Offer drink from cup to mother/doll Set cup in saucer
Neutral	Telephone	Receiver to ear Dial Converse (babble) Present telephone to other Replace receiver properly
Female	Small unisex doll with chair, table, and bed	Set doll in chair/bed Lay doll in bed Arrange furniture Stand and walk doll Child sit on toy chair
Female	Large baby doll with dress, socks, shoes, hair brush, and bottle	Undress Dress Brush hair Feed with spoon Feed with bottle Feed with cup Cradle in arms Kiss doll
Male	Plastic dump truck, blocks, and garage	Push truck Make truck noises Push/place truck in garage Place block in truck Dump block from truck
Male	Baseball bat, glove, and bat	Throw ball Roll ball Glove on hand Place ball in glove Place hat on head Hit ball with bat

Source: Zelazo, P., & Kearsley, R. The emergence of functional play in infants: Evidence for a major cognitive transition. *Journal of Applied Developmental Psychology*, 1980, 1, 95-117.

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MUSIC THERAPY WITH VISUALLY IMPAIRED INFANTS AND CHILDREN

Natalie Werbner, RMT
(Israel)

"A toy is a toy once a toy is made, but a song is not a song until a song is played."

Before I begin on the more formal part of my presentation, I'd like you to join me in a dance choreographed by Aya who is totally blind as a result of RLF. She has a typical developmental delay. Aya made up this dance at age 4. I will sing the song in Hebrew. The song is about the days of the week. After each day the word Avodah - which means work, is sung. On Saturday, no work is done. It is a day of rest.

Please stand up. Bend your arms at the elbows, bringing your hands beside your ears. Make a fist in each hand. For each of the three syllables of the word A-VO-DAH, quickly raise your arms straight up, fingers pointing to the ceiling, and bring your arms down immediately to bent elbow position. The word AVODAH has this rhythm pattern (demonstration).

Introducing visually impaired infants and young children to the world of music can be of great benefit to them. This introduction can be made in earliest infancy and can continue to provide the children with a wealth of sensory, perceptual, and cognitive stimulation as they progress through their developmental stages (Carolan, 1973). Following are some of the areas in which music can be of value. These will be elaborated upon in the sections dealing with techniques and methods -- and in the slide presentation.

1. Utilize sounds at varying distances to develop spatial orientation.
2. Stimulate different tactile and kinesthetic experiences.
3. Encourage communication on a variety of levels: as pre-verbal; verbal; non-verbal.
4. Offer opportunities for autonomy, self-mastery, and creativity leading to self-esteem.
5. Energize, organize, provide security and structure through rhythmic experiences (Gaston, 1968).
6. Deliver appropriate cognitive information according to the child's developmental level.
7. Lay the foundation for the on-going and future enrichment of the child's necessarily limited horizons.

Let us now look more closely at some of the theoretical bases and ways music can be introduced into the life of a visually handicapped child.

The blind infant's first introduction to music, through his primary remaining distance sense, that of audition, might well be the recording "Lullaby From the Womb" developed by Dr. Hajime Murooka at the Nippon Medical University in Tokyo. It would seem reasonable to suppose that Dr. Murooka's work, centering on the sensitivity of the auditory system and the effect of noise on premature and full-term sighted infants has even stronger implications for blind infants who are so totally dependent on their auditory environment for information about their world. Dr. Murooka (1974) corroborated other medical evidence which proves that a baby reacts to loud noises before and after birth as a result of the development of the auditory organ and the auditory nerve system within the first six months of pregnancy. In the hospital maternity wards he would constantly observe newborn babies responding to the sound of heavy footsteps in the corridor or a loudly slammed door, by stretching their hands spontaneously even while in a deep sleep. As a result he became very concerned with the effects of

irritating noises on the baby's development both in the hospital and in the home. In her presentation: *Intervention Following Birth -- The Beginning*, presented at the First International Symposium on Visually Handicapped Infants and Young Children, (1981) Sandra Butcher related very dramatically to the effect of environmental noises on the premature at risk RLF infant. One way to alleviate some of the traumatic auditory experiences which such an infant is subject to, and at the same time enrich her auditory life would be to play Side 1 of the recording periodically during her long hours in the incubator. This side of the recording is of the sounds which the unborn infant hears in the womb -- the mother's body beat with the "steady pulsating of blood rushing through the mother's aorta as it passes by the uterus, together with the smoother, more even sound of the pulsating umbilical cord" (Murooka). The recording was obtained through the insertion of a tiny 8mm microphone near the head of the fetus in a woman eight months pregnant. Light classical music is added to the body sounds towards the end of Side 1 in order to help the baby make the transition from the womb to the outside world. Side 1 is primarily for use during the first two to four weeks of a child's life, at which time Side 2 with light classical music is suggested.

"Lullaby From the Womb" not only offers an early positive auditory experience, per se, but touches other areas of music in relation to the visually handicapped child: (1). It is a form of non-verbal communication between the mother and the infant. (2). It has a rhythmic, familiar, auditory structure which helps ease stress and develop a sense of security.

In the area of development of the tactile and kinesthetic senses, music can help through enhancing auditory-manual coordination. This auditory-manual coordination, according to Bower and Wishart (n.d.) comes earlier than the cognitive stage of object permanence. Music experience can serve as a reinforcement for the "reach and attainment of object on sound clue only" which in the Selma Fraiberg (1977) studies comes in the range of 0:6:18 - 0:11:1 (26 weeks - 44 weeks) with a median age of 0:8:27 (35½ weeks). Such reinforcement can be achieved through the early introduction of a variety of musical instruments, both home-made and commercial, which the baby can become familiar with auditorily, tactilely and kinesthetically as she is increasingly motivated to reach on sound. Care should be taken that these instruments are sturdily constructed and safe in terms of the baby's age. Some of the instruments can be available when the baby is alone while others should be used only in a shared exploration of sound with mother or another caring adult.

The tactile, kinesthetic process of causing an object to produce a sound, which in turn stimulates the auditory sense, gives the baby a beginning awareness of cause and effect plus a budding sense of autonomy. She can control something in her world. Bells on wide bands of elastic which the baby can either grasp and shake or can be put around hands or ankles, and small shakers made from plastic containers which are filled with dried beans, rice, etc. are suitable for this age. As the baby shakes the miniature maracas she feels, on the palm of her hand, the vibration of the contents striking against the container. This sensory experience is a foundation for later cognitive learning about sound production. An excellent resource for additional ideas on home-made instruments and toys specifically for visually impaired children is the booklet: *TOUCH TOYS AND HOW TO MAKE THEM* by Henriette Zegers. It is available from: Touch Toys, P.O. Box 2224, Rockville, MD 20852, U.S.A.

Moving to the area of vocal communication, it has been noted in work with sighted infants that though it appears that babbling is spontaneous, geared closely to body maturity and not dependent on hearing language sounds, the amount of babbling within the first six months of life is dependent on adult presence and reward (Gurney, 1973). The need for parents to "talk" to their blind infants has been stressed in the literature. Such "talking" need

not be limited to the naming of objects but can concentrate on intonation, pitch and rhythm in matching and extending the baby's own vocalizations. Here is the beginning of song, of music, which Noy (1968) describes as "a language whose origins go back to the auditory channel of communication at the preverbal infantile stage." Here the baby can be the leader as well as the follower. Her vocalizations are accepted and rewarded through the musical technique of call and response. From the initial reflections of the baby's sounds, the adult can create simple, rhythmical chants or melodies using words based on those early sounds. Ideally, the words should be those to which the baby can relate -- either as familiar persons or objects, or those which can be explored tactilely. During the baby's first year, songs with accompanying actions which relate to her own body can help give a proper body image and sense of identity. Many countries have a long tradition of action songs for babies and toddlers. These songs not only reinforce communication between parent and child in a pleasurable, joyful way but open avenues of contact between children and their culture. As visually handicapped children grow, this will be especially important for them in developing a common communication system with their sighted peers.

Given the visually handicapped infant's tendency to immobility unless adequately stimulated, and the necessity of mobility for future learning, music of a steady, rhythmical nature may serve as a lure for that mobility. Action songs with the help of an adult are a good way to inspire intentional movement. Moving along with the infant gives a sense of dance, even in the early stages when she is lying or just beginning to sit. Swinging arms together, rocking back and forth, bending legs to chest in a bicycle motion, all these give needed body contact with the adult while modelling into the baby's body patterns which she will later use on her own. For variety, one can use selected, short, orchestral music which has the added dimension of new auditory stimuli. The addition of music and the focus of movement as an art form instead of purely as an exercise program, puts the emphasis on a creative, natural experience for both parent and child, rather than primarily on treatment and curriculum.

As we approach the cognitive area of development, a new assessment tool, M-PACD -- The Musical-Perception Assessment of Cognitive Development should be of great interest not only to music therapists and educators for whom it was designed, but also to parents and others working with visually handicapped from 0-14 years. "Little or no musical background is necessary to administer the tasks on the assessment, though a small collection of specified instruments is necessary. The M-PACD is an auditory equivalent to the standard visual tasks designed by Piaget and his associates" (Rider, n.d.). That the tasks can also be used for instruction purposes makes the assessment particularly flexible and useful.

With this background material in mind, let us now move on toward actual examples of how children between the ages of 1-6 have responded to their music experience within the pre-school framework of the Ofarim Unit in Haifa, Israel.

Ofarim (Fawn) which offers pre-school services of an educational and interdisciplinary (paramedical) nature to visually handicapped children 0-6 and developmental guidance, counselling and support to their parents, is a branch of The Hannah Khoushy Child Development Centre of Rothschild University Hospital in Haifa, Israel. The multi-professional staff of the Unit includes: a coordinator who is a specialist in developmental occupational therapy, a developmental paediatrician, a psychologist, a social worker, paramedical specialists including a music therapist and a nursery school teacher, plus selected volunteers. The nursery school teacher is sponsored by the Special Education Department of the Ministry of Education and Culture.

Ofarim serves visually handicapped children who live in the northern region of Israel. During infancy and up to the age of approximately two, treatment is primarily through individualized work with parents and child and is carried out by the physiotherapist and/or the occupational therapist plus social worker and psychologist. Children enter the group pre-school program between the ages of two to three years old and attend one to three times a week depending on their needs and the distance they live from the Unit. As they become adjusted to our program they are gradually integrated into regular nursery schools in their neighborhood. When a child enters formal kindergarten under the aegis of the Ministry of Education, contact with Ofarim continues through individual afternoon sessions in music therapy and other therapies as indicated. These may be any combination of movement, occupational therapy and/or play therapy.

Music therapy is an integral part of the program at Ofarim. The music therapist spends three days a week in the pre-school working in close cooperation with the nursery school teacher and other staff. Both group and individual music sessions are part of the everyday schedule.

The role of music in group sessions serves several functions; (1) enhancing the social interaction; (2) strengthening the cognitive material being presented by the teacher and (3) motivating structured and spontaneous physical activity. Music also provides a future meeting ground between sighted and visually impaired children in which much of the language used to explain the experience reaches the sensory experience. The necessity for such experiences has been discussed by Santin and Simmons (1977).

Consider the learning taking place as a group of visually impaired two to three year olds first explore and then play tambourines in accompaniment to the songs played by the therapist. The children examine the roundness of the frame, the head, and the small jingles. They experience first-hand, three different textures, all round: the plastic or wood frame; the nylon or leather head; the metal jingles. They have immediate access to the outside and the inside of the object and to its other dimensions. Some of the children discover on their own new ways to use the tambourine such as wearing it on their head or knocking it against various parts of their body. With other children we must bring these possibilities to their conscious awareness through verbal and non-verbal means. But, as one of our exceptionally articulate and gifted children remarked when she was four years old, "It's much better to discover things for yourself than to have someone teach you."

Thus, what appears to be a common musical experience for pre-school children and for professional percussion players, holds for the visually impaired child a multitude of developmental opportunities, ranging from a sense of inner joy and personal expression within a social setting to tactile and kinesthetic experiences involving laterality, directionality, fine muscle coordination as well as auditory stimulation and cognitive development.

In group sessions the children initially receive instruments from only one family -- such as tambourines of different sizes and materials. In this way they are not only introduced to the concept of families of instruments but they have a clear auditory experience. Later, as they become familiar with different instruments during their individual sessions, some of them request specific instruments for group time. In such sessions the children take turns playing the different instruments so that each child has a concrete as well as abstract experience with each instrument. Except for starting and stopping together, the children are allowed and encouraged to respond in their own way -- this is particularly important for our new group of children, many of whom are multihandicapped. Requiring them to perform in precision at this stage would be, in this therapist's view, a defeating experience for many of them since each child has his own body rhythm. Actually, this must be considered when working with any group of young children. At a later stage, the precision

demanding to play on the beat or in varied rhythm patterns, becomes a goal toward which to work. Meanwhile the children gain a sense of the musical structure through the therapist's playing and the singing of other adults.

Great attention is paid to the songs which we introduce to the children in our program. For young visually impaired children, the words and the melody should be within their easy grasp so that truly meaningful involvement is insured rather than mere echolalic responses. Finding such material is a great challenge and often songs must be translated, created, or tailored to the specific needs of the children. Songs which include the child's name and the names of family members help to give a sense of identity. Songs which require active identification of different body parts help in the continuing development of body image. Songs about activities of daily living such as: getting out of bed in the morning; washing; dressing; eating; going to nursery school by foot, bus, car or van; playing together; fighting and making up; saying good-bye and going home; going to sleep at night; all help in familiarizing the child with the rhythm and sequence of day to day life. Acting out a lullaby which tells the child to rest his/her head on the pillow and go to sleep serves to make the going-to-sleep process a personal and more welcoming one than do some of the more traditional lullabies with threats of falling out of cradles, being spanked, etc.

Traditional holiday songs give sequence to the year. For the two to three year age group every effort is made either to adapt these songs or to use less complex songs especially composed for this age group. If artifacts or food are part of the tradition of the holiday, these objects are passed around to give tactile reality to the words being sung. Naturally, if food is involved, the children taste it and often participate in its preparation.

All parents are requested to bring a list of their child's favorite music so that there will be continuity and easy transition between home and the Ofarim program. Children become aware of each other's favorite songs and are even exposed to words in different languages, depending on the background of the children in the group. Thus, over the past four years all children have heard, and some have learned songs in Hebrew, Arabic, and English.

Tali, who is totally blind also suffers from grand mal epilepsy. At the age of 4½, during her individual sessions, she would review the greeting song sung to each member of the group during the morning circle. When she came to Naim's name she would begin to sing in Arabic and return to Hebrew for the other children. This review showed not only the strength of her auditory memory in learning the names of all her classmates, but her understanding that the same greeting was expressed to Naim in a different language. Naim, in turn, learned all the songs in Hebrew as well as those Arabic songs the therapist managed to master with the help of Naim's home teacher.

From the group experience we now move to examples of work with individual children.

Elisha

Elisha was born in July 1980 in approximately the 30-32nd week of pregnancy. His birth weight was 1.460 kg. His neonatal period was extremely difficult. Blindness as a result of RLF was discovered between three to five months. He is a child with quadriplegic cerebral palsy and the muscle tone in all his limbs is spastic. He cannot sit by himself. At approximately six months of age he was discovered to have Hypsarrhythmia, a convulsive disorder. He was treated for this and recovered. However, he later developed grand mal epilepsy for which he currently receives anti-convulsive therapy. Despite these many handicaps Elisha appears to have age appropriate social and emotional development.

When Elisha first entered the program at the age of 2 years, 4 months, he screamed for hours on end, even though both his mother and his aunt were with

him. His expressive language was limited to mostly names of family members and objects such as "carriage, home" etc. His comprehension level seemed much higher. He liked to hear stories either read or told to him.

At Ofarim, his first favorite instruments were those made of wood such as rhythm sticks and wood blocks. A well-known folk song about a set of clocks soon became his favorite new song. He was gleeful as the therapist held his hands and helped him beat out the quicker and quicker ticks of the clocks. The theme song from "Pinocchio" which he had heard regularly on TV last year, was the bridge song from home to school. His mother and aunt patiently sang it until the therapist learned to play and sing it since no published version was available. There is a poignant reality to his being drawn to this song since he, as Pinocchio, needs someone to help him move his body. In future years, the words to this song may have particularly painful meaning for Elisha as he realizes his extensive physical limitations. The words are: "Good morning world. How are you all? I've come off my strings. I'm now a real boy. Just like everyone else, just like everyone else." However, at this time the song continues to delight him and it opens his individual session each morning.

After Elisha was introduced to the mallets and the drums, there was no doubt that he had found "his" instrument. Soon the word "sticks" was added to his growing vocabulary. He tended to repeat new words as he heard them and then to gradually incorporate them for purposes of communication. In Hebrew, the word for drum sticks or any other kind of mallets is "maklot" and this was difficult for Elisha to pronounce. He said, "ma-lot." He couldn't wait to get the sticks in his hands and talked about them even at home. As soon as he heard the music therapist's voice, he said, "ma-lot." Even now, when he knows and can identify all the staff members by name, he often teases the music therapist by calling her "maklot" which he can pronounce properly.

Elisha, whose body is so tense, whose arms tend to be bent at the elbows and drawn upwards towards his shoulders, his hands clenched, is increasingly motivated to bring his arms down and open his hands. This is especially so during his individual music sessions when he holds his favorite pair of rubber-tipped mallets and beats on an adapted drum set. The set includes a small drum placed in the middle of the table, a large and small tambourine to the right and a set of four different-sounding cans to the left.

Elisha can voluntarily open his hands to receive the sticks when asked to do so. He can grasp and hold them securely though freely enough that they can bounce on the instruments. He has better control of his right hand than his left. Until recently he tended to beat only with his right hand when working independently though he has also started to beat with his left hand.

In order for him to be in the approximately traditional drumming position, and allow the therapist to co-act with him, he sits between the therapist's legs. This also gives him some of the support he needs to sit upright. Playing time is balanced between Elisha being guided in the beating and independent beating, the majority of the time being spent in guided patterns. This is done so that he will feel the proper muscle groups needed to beat the drums and the possibilities for a variety of rhythm and tone patterns. If his body stiffens up, activity is stopped immediately until he relaxes again. His independent drumming was initially very weak. He is gaining in strength and control and can beat more loudly and continuously now which is a great satisfaction to him.

After the first several months at Ofarim, he became so enamoured of drumming that he began to use the silverware at home to beat on the table and dishes. His family picked up the message and provided him with wooden spoons and various bowls until he received a gift of a tambourine similar to the one he uses each day at Ofarim. Since he prefers the original type of mallets to any other we have tried, he was given an extra pair to use at home. He often asks for his sticks and as with most avid drummers, his parents sometimes have

to tell him "enough drumming for now."

To expand his musical horizons and still use his sticks in which he so delights, playing on resonator bells has been added. This gives him a melodic and harmonic instrument as well as primarily a rhythmic one. The same combination of co-active and independent action is used. Elisha's range of motion from left to right is gradually increasing. Playing the resonator bells involves him in crossing his midline as well as basically lateral up-and-down movements.

Elisha's thirst for new words and his appropriate use of them has provided the therapist with many opportunities to introduce important concepts. A traditional children's song about two hands has been adapted to include left and right. The song also helps to reinforce the personal pronoun "I" which is still not completely under Elisha's command. The adapted version of the song states: "I have two sticks, tra, la, la, la, la, la." As each hand is mentioned, the therapist guides Elisha's hand to play separately. During the rest of the song both hands play together. Here is a simple example of how the kinesthetic experience and the auditory musical messages of melody and rhythm can be combined with concept teaching. The many repetitions needed to consolidate the learning are natural within the musical framework.

Another concept song deals with up, down, and side to side. The directions describe the levels where Elisha must place his sticks to play the drum and the instruments below and to the sides of it.

Elisha has become the official drummer and resonator bell player for holiday and birthday parties. This gives him a more active role in the group. Because of his new status as a big brother, it has become important to help find ways in which Elisha can help other children and thus feel a sense of pride and maturity. A natural opportunity presented itself one morning when Yodfat could be heard in the main room, crying inconsolably. The therapist suggested that we bring the resonator bells from the music room where we were, into the main room since Yodfat really liked the sound of the bells. Elisha agreed and as soon as we were positioned and began to play, Yodfat ceased crying. She also began to smile. This was described to Elisha as well as reinforcing what he had heard -- that Yodfat suddenly stopped her crying. Everyone praised Elisha for his help and joined in singing Yodfat's favorite songs.

Though for Elisha, the intentional muscular activity involved in playing contributes, as does any intentional movement for him, to his spasticity, the other benefits he derives from active involvement in music far outweigh the difficulties it causes him. I might add that the physical therapist concurs heartily with this.

Chamutal

Chamutal was born in January 1981 in the 28th week of pregnancy. Her birth weight was 1.200 kg. Her neonatal period was complicated by respiratory distress syndrome and many other problems. She received seven days of mechanical ventilation, an exchange transfusion and multiple blood and plasma transfusions. She has RLF with light perception. Chamutal spent many months in the hospital after birth not only because of her physical complications but because her parents were not sure they would be able to bring up a blind child. Through consultation, and exploration of services for blind children and their families, Chamutal's parents did decide to bring her home. Chamutal, who has no other handicaps, is developing normally for a premature RLF child.

Chamutal began her individual music therapy sessions on a periodic basis, when she was almost 1½ years old. As with many children in the Ofarim program, her parents felt that she was especially attracted to music. At home the whole family enjoys listening to records, singing and playing the recorder. Her parents were interested in how to expand Chamutal's involvement. Even at

that time, Chamutal would turn instantly in the direction of any musical sound and try to reach out for the object making it. Now, at the age of two, and mobile, her response to hearing one adult after another start to play a recorder, was to quickly head towards each sound source in order to collect all the instruments. She will trade instruments when encouraged to do so and has even begun to initiate such trades. If she receives the recorder up-side-down she can right it and put it into her mouth properly. Recently she was delighted and surprised to hear and collect several recorders of different sizes and weights: i.e. sopranino, soprano, and alto; some made of wood, some of plastic. A different balance is required to bring each of these to the mouth. Chamutal managed successfully.

Not only have these experiences been positive in relation to increasing skill in spatial orientation, they have served a true musical purpose, giving Chamutal the chance to participate on her own level in ensemble with her mother and the therapist. Her stance, her facial expression, and her rhythmic blowing, show that she is acutely aware of her role in re-creating her favorite songs. She has begun to sing certain key words of songs she likes and to "ask" for songs by those words or by humming the song.

Chamutal is full of curiosity. In her individual sessions she shows increasing pleasure in examining new instruments such as the small electric organ, the piano and the violin. She initially resisted holding the violin but she has now begun to make friends with that instrument. Since the violin is too large, Chamutal needs help in holding it. Though this detracts somewhat from the experience which would include a more total body balance, she is receiving a rich proprioceptive experience in her upper body, plus a direct experience of the vibrations she produces as she draws the bow across the strings. During exploration of the contours of the instrument, Chamutal's hands are guided in such a way that she gains a sense of its symmetry; comparison is made to the human body -- especially in regard to the neck, shoulders, waist, and hips. The parts are named as they are touched.

This gestalt-type process of touching, playing, and naming is followed with every instrument introduced to the children. The extent of the cognitive content is determined by the developmental level of each child.

NOTE: Extensive references are available from Natalie Werbner

EFFECTIVENESS PROGRAMS AND SERVICES:

ONTARIO FOUNDATION FOR VISUALLY IMPAIRED CHILDREN, INC.

Norma Kelly
(Canada)

The Ontario Foundation for Visually Impaired Children founded the High Park Forest School in 1975. Its purpose is to provide exemplary education at a pre-school level for infants and young children from birth to six years who's primary disability is visual impairment or blindness.

We are aware that early nurture and training of a blind child is a specialized task. The parents, lacking previous experience and specialized knowledge, often find themselves overwhelmed by the situation without support and guidance.

For some blind children who leave home for residential school at age six, it is even more important that they have suitable pre-school experiences to help prepare them to enter school as somewhat independent children eager to participate in more formal education.

The Foundation was set up in response to the growing appreciation of the importance of early childhood experiences to the development of all children and in particular the serious void for Ontario's visually handicapped children. The Ontario Foundation for Visually Impaired Children is governed by a volunteer Board of Directors responsible for policy and fund raising. The Executive Director is appointed by the Board and directs the High Park Forest School and its multidisciplinary staff and consultants.

The Foundation is prepared to serve children throughout Ontario however, due to lack of expansion funds and commitment from the government to support such needed programs, this is not possible at present. The children we serve reside in and around the Metropolitan Toronto area.

The program at the High Park Forest School is partially funded by the Province of Ontario through the Ministry of Community and Social Services, Day Nurseries Branch. They fund approximately only 50% of our total program due to the limited funding criteria. Areas not covered by funding are; travel for home visits, home programming for children who are under two years of age, or children from out of the area who come to the school for assessment, home programming and parental guidance. The costs of our assessment team or the salaries for such staff as our physio-therapist, or consultants are not funded. These services are fortunately covered by funds raised through the private and corporate sector.

Personnel

The High Park Forest School has a multi-disciplinary team including the director, four teaching staff, and a team of consultants. All teaching staff and the director are graduates of recognized Colleges in Early Childhood Education plus are in other fields of children's services such as Child Care, Orientation & Mobility and Music. To augment the teaching staff, we have two driver-aides who are responsible for transporting the children in a safe comfortable manner. During the remainder of the day, the aides assist the staff in projects, provide outings in the community for the children or help in the general playroom area.

Our Consultant Team consists of a physio-therapist who works at the school one day per week, and when needed, a speech and language consultant, and an ophthalmologist. A paediatric-psychiatrist who is very aware of developmental deviations and behaviour patterns of young children is also available to

work with and counsel families as needed. Our psychologist who does the more formal testing, is a key person in the assessment team and very knowledgeable in the area of blindness and visual impairment where it impacts on learning skills.

Volunteers are also a valuable source of assistance at the school. We have only a small core group of faithful volunteers who come in on a regular basis and are well known to the children. Students from the Community Colleges are welcomed for a block placement of at least three weeks, or a minimum of two full days per week for a period of three months. We do not accept students for shorter periods than this as it is too disruptive to the children.

Criteria for admission to High Park Forest School day Program

A child is eligible for screening into the High Park Forest School program when he has reached his second birthday, suffers from a visual impairment which is impeding his developmental progress, and is a resident of the Metropolitan Toronto area.

The child must be in the care of an ophthalmologist and have had an eye examination in the past six months. He must be seen by his family physician and be considered by the physician to be able to participate in the program, and have his immunization record up to date.

The initial assessment of the child at the school includes the

following:

- 1) Observation of the child and the child/parent interaction
- 2) Interaction of the child with other persons, general reaction of child to playroom area and stimulus of other children
- 3) Level of functional vision and use of vision
- 4) Child's maturational level
 - a) social skills
 - b) physical development
 - c) mobility and orientation skills
 - d) speech and language development
- 5) Child's over-all appearance, general health and stamina, emotional level, and ability to function at this time.
- 6) A medical history is taken and the child's eye report reviewed.
- 7) Identification of other impairments such as neurological problems. A report from the clinic or supervising physician must be received before admission.

Who do we not admit?

- 1) We will not accept a child into the program if visual impairment is not a major factor, but we may see the child on an out-reach basis. This would include the child who loses the vision in one eye and the other eye is still healthy.
- 2) The severely neurologically damaged child who requires a great deal of medical involvement, possible nursing care and more physiotherapy than we can provide.
- 3) A child who suffers from an emotional or behavioral disorder which is disruptive or a danger to the other children, or a child who cannot be transported in a safe manner.
- 4) We will not accept a child into the program unless we have the support of the parent or legal guardian, and a willingness to work with us.
- 5) The profoundly retarded child. This does not include the category of children known to all who work with the visually impaired. Those children who fall into the hands of psychologists and pediatricians who have little or no knowledge of visual impairment and blindness and therefore brand these children as retarded, having used tests designed for the sighted and questions which are all visually oriented. For this reason we have formed our own assessment team which will not amend or adjust sighted scales for the blind but will use a battery of tests designed for the blind and partially sighted as well as

our clinical observation based on our experience and knowledge of developmental norms and the developmental norms of the blind child.

Sources of Referral

The parent must make the referral, however they are usually encouraged to do so by their child's ophthalmologist, a C.N.I.B. worker, a public health nurse or a paediatrician.

The Hospital for Sick Children in Toronto has a very active Eye Clinic where the majority of our children are seen, consequently most of our referrals are from that source.

Home Visits

All children who are to be admitted to the program on a full or part time basis will be visited in their homes by an assigned staff person. This is to assist us in understanding the home environment and possible sources of family stress as well as the child's ability to cope in a familiar setting. It is also a good time to observe family interactions.

Visit to the School

Prior to admission, the entire family will be asked to visit the school, and the child will be met by the person who made the home visit and who will assist him/her to explore the materials and new setting. The parents will be interviewed regarding their expectations of the school, what they hope to achieve for their child, their own particular needs and their probable degree of involvement. In turn I offer them information regarding the program and our expectations of their involvement. I would describe the need for their support and assistance in carrying through at home the goals set at the school.

The parent is asked to accompany the child and remain with him/her in the program until the child settles in. A date for admission is set and transportation is arranged. There are no fees charged.

Program on Admission

Our first aim is to make the child as comfortable as possible in the new surroundings. The child's mother or guardian is almost always in attendance for the first few days or longer. Since observation is by far still the best assessment tool, we observe and record the child's reactions, likes and dislikes, areas of fear or over-reaction etc. The child is guided slowly but systematically through the various aspects of the program and its activities. Few demands are made on him. Activities are introduced and he can participate but not forced to do so. As he/she moves into the program and begins to participate, the mother usually withdraws and allows the child more independence to explore on his own. This allows the mother time to sit back and observe her child and to compare his or her skill level with those around. If her child compares favourably the mother's anxiety level will drop, if however her child is not at the level of his or her peer group, the anxiety level accelerates. How the parent handles the first few days in the program gives a lot of vital information about the family and its expectations for the child. When the child has settled in the program and before an individual program is set out for the child, a Skills Inventory will be done. Since much of the information required will need a lot of observation and past knowledge, it is helpful if the mother assists. This also helps the mother to see her child as he really is and will point out a lot of positives which she probably has overlooked or taken for granted. If done in a supportive

way it need not be a negative experience but a challenge and a new focus.

The Skills Inventory will record functioning levels in areas of 1) gross motor, 2) fine motor, 3) self-help, 4) socialization, 5) cognitive development, 6) speech and language, 7) visual acuity.

When the Skills Inventory is completed and the child has been in the program long enough to feel secure and staff have had ample time to observe and get to know the child, it is time to set out an individualized program plan. In implementation, the plan should be a team effort with the appropriate areas designated to the person best qualified to teach that skill.

After a pre-determined period of time a review should be done to determine the child's present level of functioning. If the program has been effective, there should be significant changes noted. Changes can be made before the review conference if some of the program plan is not having the desired results.

What is unique and different about the High Park Forest School?

We like to feel that we are unique and special for several reasons: the first being that in Canada we know of no other similar facility which is designed entirely for the visually impaired or blind pre-schooler. In the future we hope that the High Park Forest School will be the "hub of the wheel" with small outreach centres spread throughout Ontario.

Our physical setting and our building is interesting in that we are situated in a two hundred acre park near the core of the city. This is an ideal location in that there are no traffic or industrial noises close by. There is ample natural light having almost three full walls of window area which are set low enough for the children to peer out and for the sun to shine in. For outdoor activities, the children can play on the hills, hear the birds, pick beans from their garden or just explore the varying terrain. In winter, there is skating, sliding on the hills or cross country skiing if there is snow.

The program is somewhat different than I am accustomed to seeing as each child is treated as an individual who is free to develop at his or her own rate. There is little pressure to conform to group norms. For instance every child does not have to go outdoors at the same time or do arts and crafts, or group play at a scheduled time. There is lots of time for free expression and the tools and props for learning or creative play are always available, plus staff to guide as needed.

Music is a favourite activity and there is ample opportunity to participate in the many music circles, or in individual or small group sessions with the music therapist.

Orientation and mobility training is begun as soon as the child is ready and capable of learning the techniques involved. It is an on going process and as in most areas of learning, is done frequently through play. We have been very fortunate over the years in having acquired through donations, some excellent equipment and toys, some of which were designed by staff and made for us by a volunteer carpenter.

As our main playroom is 48' by 80' or approximately 14.6 m by 24 m, a child soon learns to cross open space where there is ample room for gross motor activities, such as tricycle riding. Various climbing and tumbling equipment is available at all times. The staff/child ratio is also good in that we aim never to exceed (a 3 to 1) 3 children to each staff person. This is not counting the volunteers, students or parents who are frequently there to assist.

Welcome at any time, the parents may participate or observe and are free to come and go as they wish. If or when questions or issues arise, there is always someone available. There is also contact between staff and parents on a weekly basis by means of the child's weekly record book which goes home each Friday, telling of any special events or significant happenings, or just

what kind of a week the child had. The parents are requested to respond.

The area of parent involvement and counselling is probably our weakest area at this time. As parents change, needs change, and we will be taking a closer look at this area and making some significant changes in policy before school re-opens in September.

We will also be revamping policy and procedures for our out-reach program, which serves children under 2 years of age and those who for geographic reasons cannot attend the High Park Forest School except for short periods of time.

Our assessment team for doing both functional and clinical assessments is in the early stages of development, but we are looking forward to the challenge and new dimensions this brings.

HOME BASED AND CENTER BASED PROGRAMS

FOR VISUALLY HANDICAPPED CHILDREN

BIRTH TO FIVE YEARS OLD

Susan Kurtzman - Mary Lonergan
(U.S.A.)

Introduction

This is Mary Lonergan and I am Susan Kurtzman. We are pre-school education consultants in the Children's Services Division of the State Board of Education and Services for the Blind in the state of Connecticut, U.S.A. Our program is an itinerant one serving the entire birth to five year old population in the state of Connecticut who are diagnosed as visually impaired or legally blind. There are five pre-school education consultants and one social worker in our division and we serve over 120 pre-school children at this time. The Children's Services Division also serves older children ages five to twenty-one. The agency has several other divisions that provide service to adults including a Vocational Rehabilitation Division and Mobility Department.

The pre-school program began six years ago with one education consultant serving the entire birth to five population in the state. It was and is the feeling of the Director of Children's Services, Dr. Robert Long, that the critical years of learning from birth to five are essential for blind and visually impaired children to gain the basic skills they need for their later success in school. Additionally, it is the philosophy of the pre-school program that it is important for the parents of visually handicapped children to gain access to the knowledge and skills that will assist them in gaining the most for their children from the educational facilities in their home communities. By having education consultants work with very young children and their parents in the home and as liasons with school programs an early awareness and understanding of the resources available to the child is built.

The Board of Education and Services for the Blind pre-school program is funded by both federal and state funds. This funding provides for the consultant's transportation and salaries, educational materials for the children that relate to the visual loss, and any tuition or ancillary services needed.

We work closely with the local school systems to identify and provide an appropriate educational program for each child. This process begins with a Planning and Placement Team Meeting which identifies the child's needs and plans how best to meet them. Although a school system is required to identify any handicapped child as early as birth they are not required to provide educational programming until the child reaches the age of three. It is before the child is three years old that our program is the primary one. When the child is three, the school system becomes responsible for educating the child and formal schooling generally begins. Our pre-school services continue in conjunction with the school district until the child is five.

The state of Connecticut is 4,682 square miles in area. Each of the five pre-school consultants covers a designated geographical region and works with local agencies and educational facilities to provide center based programs for our children. The majority of children are taught in their own homes by the education consultant before moving on to a school based program as well.

For those children who are multiply handicapped, and there are many of them, we work in conjunction with other professionals to provide comprehensive services. In these instances, we are case managers and coordinate the various

services the child receives.

The following slide presentation further explains our program. After the slides, we will be happy to answer any questions you may have. The children in these slides represent a typical sampling of our caseloads.

Slide Number

1. This is Thomas, 16 months of age. He has been served by the Board of Education and Services for the Blind since the age of 8 months. He is blind due to Retrolental Fibroplasia (RLF).
2. Theresa is 11 months old, she has been served by our agency since age 7 months. Theresa is totally blind due to microphthalmia.
3. This is Jose, a 5 year old child who is blind and has mild cerebral palsy.
4. Eric is a 5 year old with low vision as a result of cortical blindness. He has been in our program since he lost his vision at the age of 2.
5. Melissa is a 4 year old with retinal colobomas. She has been in our pre-school program since age 2.
6. 3 year old Chris is typical of our multiply handicapped population. Many of these children have motor difficulties or delays that require adaptive equipment. The family's insurance covered the cost of this wheelchair.
7. John is 4 1/2 and severely developmentally delayed due to chromosomal damage. He is cortically blind.
8. Sandy is 4 years old. She is one of our deaf-blind children.
9. In both our home and school programs we begin our services with an evaluation of each child. The following slides give some idea of the evaluation tools and teaching aides we use. We generally use one or more of the following scales when evaluating a child.
 - Oregon Project Skills Inventory for Visually Impaired and Blind Preschool Children
 - Reynell-Zinkin Scale
 - Callier-Azusa Scale
 - Hawaii Early Learning Profile Activity Guide (H.E.L.P.)
 - Portage Guide to Early Education
 - Early Learning Accomplishment Profile (Early L.A.P.)
- All of these are informal developmental check lists that help us assess a child's baseline skills.
- The Portage and Early L.A.P. are very visual in nature. Therefore we more frequently use the Reynell-Zinkin Scale, the H.E.L.P., or the Oregon Project which is specifically designed for visually impaired and blind pre-school children up to age 6. We use the Callier-Azusa Scale, when appropriate, for multiply handicapped children.
10. The flashlight and pen light with color transparencies are used in visual stimulation programs for all types of activities such as fixation, tracking, and color identification. The circles are part of a tactile stimulation kit and are used for texture discrimination and sorting.
11. This shows an assortment of the educational materials we use with pre-schoolers. Four part puzzles, stacking rings, and carpenter's bench are all used for hand-eye coordination, visual identification, color identification, and so on. The infant mirror and picture cards are used with low vision children.
12. These manipulatives are used with infants and young children for auditory, visual and tactile stimulations.
13. Self-help skills are encouraged by using the zip, button and buckle frames seen in the front row. Books, shape sorters, slinky, and stacking cubes are some of the teaching tools we carry with us.
14. A child is referred to us through any one of many sources. Connecticut State Law Section 10-305 requires eye doctors to refer children who are legally blind to our agency in writing within 30 days. Oftentimes, pediatricians,

parents, visiting nurses and social workers at hospitals or agencies will make the referral. Since many of our children have additional handicaps other state and private agencies serving the child may refer him to us. Although we offer services from birth, many children aren't referred to us, unfortunately, until they are two or three years of age. We begin serving them as soon as they are referred.

15. Once a referral is made, Deborah, our social worker, makes a home visit to meet the child's family and complete the intake process. During this visit, she gathers medical and other pertinent information to be used by the education consultant. Deborah is the first contact the family has with our agency.

16. The social worker gives the information in writing to one of five pre-school education consultants. As each consultant works in a different region of the state, the children are assigned based on geographical location. The pre-school consultant makes an appointment with the school or parent at home to visit the child and begin evaluation for services.

17. The consultant's initial visit provides an opportunity to meet the family and establish rapport with the child.

18. When the child is comfortable, the evaluation is begun. Here Mary and Faith evaluate 11 month old Theresa. We have found team evaluations to be very effective. Education consultants bring all the materials necessary to complete an evaluation and the entire process can take up to two months. We evaluate the child's abilities in all developmental areas. These areas include:

19. GROSS MOTOR, such as sitting

20. FINE MOTOR, playing with hands at midline

21. EYE-HAND COORDINATION

22. COGNITIVE SKILLS like problem solving and basic concepts such as "in" and "out" as well as sound localization. Many activities encompass several skill areas at once.

23. For instance, notice that Brian, who is a legally blind albino child, is working on completing a four piece form board. Faith is evaluating his cognitive skills, his ability to use his vision efficiently, his fine motor skills, and she has noticed his tendency to W-sit, which is a maladaptive sitting position that could result in an additional referral for physical therapy.

24. Cognitive skills are evaluated using blocks.

25. Here Susan is working with Christine, 20 months old, on a depth perception skill that also evaluates hand-eye coordination, color identification and size discrimination. The plastic set of dishes was used to involve Christine in imaginative play.

26. Faith is seen here evaluating Brian's visual efficiency which includes working distance, preferred fields of vision, lighting preference and tracking ability.

27. Self-help skills, such as feeding are part of the evaluation process.

28. Social skills and interactive play are also important skills.

29. Although most children are evaluated at home, some evaluation is done in the classroom. This is Lydia, who is blind due to RLF. Her independent mobility skills are being evaluated. Notice the use of the tactual cues along the classroom walls.

30. After evaluation the consultant works with the family to plan and implement a home program. Home programs are highly individualized and are designed to meet each child's needs as determined by the evaluation process. We are usually able to see the child one hour per week, although the amount and frequency of service depends on the child's needs and the education consultant's schedule. Two year old Christy's tactile defensiveness (as evident by the position of her hands) makes her hesitant to explore and play appropriately. Mary is working with her to help overcome this problem.

31. Although we sometimes work with the child alone...

32. parents are usually present to observe the teaching sessions because they are the ones to carry through the home program. Here Brian's mother participates in the teaching session as Faith instructs her on appropriate activities to work on with Brian throughout the week. Although different for each child, typical home instruction emphasizes visual stimulation, other sensory stimulation, improving cognitive, motor, and self-help abilities and developing appropriate social and play skills.

33. This totally blind child is working on the concept of Left to Right by sequencing large pegs, which is a pre-Braille skill.

34. Our helping the parents to understand their child's visual abilities and limitations makes them an integral part of the child's education. Eric's mother is encouraging him to use his residual vision with materials provided by our agency.

35. Because of Chris' multiple handicaps it is especially important for his mother to understand and follow through on his visual stimulation program. He receives help from Easter Seal Rehabilitation Center and the State Department of Mental Retardation in addition to our agency's services.

36. Independent self-help skills such as drinking from a cup are an important part of three year old Christopher's home program. Independent skills are crucial because they make the life of the child and family more enjoyable.

37. Chris, who is hydrocephalic in addition to being totally blind, is just learning to explore his environment. He still requires a great deal of help from his mom.

38. Ryan, who has decreased vision due to RLF, also has some motor delays. Physical therapy is a large part of his program and his mom reinforces these skills at home. Ryan receives physical therapy from Easter Seals, paid for by BESB.

39. Christy's dad is following through on a program designed by the occupational therapist and our education consultant. Occupational therapy is again provided by Easter Seals and paid for by BESB.

40. Social interaction is a large part of every home visit. Here Matthew's mother encourages this skill.

41. Parents are an important part of our home programs and we try to involve one or both parents as much as possible. This is Christine with her dad, who is able to attend our weekly sessions as he works at night. He assists Christine's mother and the education consultant in all aspects of her education.

42. Siblings are also important. They may have difficulty adjusting to the amount of attention given to the handicapped child by parents and home teachers. They are therefore encouraged to participate in the teaching sessions. Gail, age four, learns how to help Chrissie, age two, who has low vision due to glaucoma and cataracts.

43. Four year old Katy enjoys helping her brother Matthew.

44. Repetition and reinforcement are keys to our home programs. We have found that parents are the best teachers.

45. Because many of our children have handicaps in addition to blindness, we are not the only agency serving the child in the home. Two year old Matthew is cortically blind and has severe cerebral palsy. He receives the services of a physical therapist and occupational therapist at home. Here his physical therapist and his mother work with him together.

46. Communication and cooperation between our teachers and these other therapists is essential to Matt's progress. As case managers we coordinate and pay for these additional services.

Insert 53. The majority of our children attend school programs outside the home. Some children begin center-based programs very young, even as toddlers. We should reiterate that Connecticut State law mandates that all children be evaluated and provided with an appropriate educational program by

age three. This means that a child's home school district is responsible for providing him with an education that meets his needs.

Placement decisions are made and reviewed at annual Planning and Placement Team Meetings. The team consists of the parents, and all professionals involved with the child, as well as representatives of the school district. We are an integral part of this team.

47. As such, we are often responsible for locating and evaluating school programs. Some of the things we look for include: a good assortment of age appropriate toys and materials that teach a variety of skills and are readily accessible to the children. Note the mobiles that can be used for visual tracking, the wide range of manipulative toys and the variety of special positioning equipment, including mats and wedges.

48. This public school program was designed for highly distractible pre-school children with learning problems. The design of the room encourages physical exploration and includes tables for sand and water play. Note the overhead moveable spotlights used to draw the children's attention to specific areas of the room.

49. This challenging environment, part of the same program, focuses on kinesthetic and tactile experiences. When walking the obstacle course problem solving and sequencing skills are developed.

50. Individual work spaces, highlighted by special lighting provides good contrast and a minimum of distraction.

51. This public school classroom provides many opportunities for imitative and imaginative play and is well equipped with child size furniture.

52. Well designed classroom space is important for group and individual play skills. Separate areas are designated for individual tasks and the environment is open, easily navigated, and well lit. The teacher is able to work with a small group when necessary yet independent work takes place on the carpet in the background. Appropriate peer groups are a prime consideration when choosing a program.

54. Some of our visually impaired or blind children with no additional handicaps attend private nursery schools in the neighborhoods. In these cases, we primarily serve as consultants, assisting the staff in fully integrating the child into the daily routine. When needed, we do provide direct services to the child within the school setting. We also monitor the child's progress and development throughout the year and often continue the home program to work on any skills the child may be having difficulty with in school.

This is Melissa, a four year old child who attends a nursery school in her neighborhood. She has coloboma of the retina with severe loss of central vision. Melissa was placed in this school by her home school district who pays her tuition and is reimbursed by BESB.

55. Service to Melissa at school is consultative but a consultant visits her weekly at home to give added support and individual teaching for the tasks she finds difficult at school.

56. This is Frankie examining the tricycle. He is totally blind as a result of extreme premature birth and RLF. Frankie attends a nursery school in his neighborhood. He is seen here with his one-to-one aide who is funded by BESB. She is there to give Frankie extra time or instruction when needed so that he can participate in the school activities with his classmates.

57. Eric, the child building the bus out of blocks, requires more direct help within his classroom from the educational consultant for the blind because he is rapidly losing his vision due to a degenerative retinal disease.

58. Our children with multiple handicaps attend special programs run by their own school districts or other agencies such as the State Department of Mental Retardation or Easter Seals. The little girl with glasses is Mary Ann, a three year old with congenital glaucoma, seizure disorder, learning disabilities,

and a heart defect. She attends a pre-school class in her home school district with other multiply handicapped children. Before she reached mandated age, Mary Ann, like most of our children, was served in her home on a weekly basis by our education consultant. Now an education consultant consults to this program and continues to see her at home periodically.

59. In all programs for the multiply handicapped the emphasis is placed on developing self help skills. Since most of these children are developmentally delayed, much time is spent teaching such skills as: drinking . . .

60. eating . . .

61. dressing . . .

62. toileting . . .

63. exploration of toys and the environment . . .

64. and play skills.

65. Our consultants are there to help design these programs and explain to the school staff how the child's visual impairment effects his ability to learn these skills.

66. Other specialists are there to assist the child in developing . . .

67. gross motor skills

68. and

69. fine motor skills

70. Because of the needs of these multi-handicapped children, most programs provide ancillary therapy services.

This is three year old Amy. She is hydrocephalic and has left hemotosis and seizures in addition to her low vision. Amy receives physical therapy, speech and language therapy and occupational therapy as part of her school day. Since the therapy and educational components work closely together, Amy's fine motor skills are reinforced during speech therapy.

72. Since independence is the goal, Amy is encouraged to move from the speech room back to her class on her own.

73. Her physical therapist works with her twice a week.

74. For Matthew a vision stimulation program cannot even begin until proper positioning is acquired.

75. Here he works with his physical therapist to raise his head off the mat.

76. A very difficult task for him.

77. Jean-Paul, who has cerebral palsy and is cortically blind, works with his occupational therapist once a week as part of his total program.

78. Play skills are developed with a great deal of support from the therapists.

79. Interactive play is encouraged even at this early age of eighteen months.

80. Careful records are kept by therapists and teachers and are shared during regular staff meetings.

81. Multiply handicapped children, like Sandy, who is deaf-blind, can also be provided with a one-to-one aide funded by BESB.

82. The aide works under the direction of the classroom teacher and our education consultant . . .

83. to integrate the child into the classroom activities.

84. Coordination of home and school programs is critical particularly for children with more than one handicap, who often have many professionals working with them. Here Mary is observing Jean-Paul's visual responses during physical therapy while the classroom teacher and his mother look on. The education consultant serves as case manager for this child's program.

85. The parents of visually handicapped children in Connecticut have formed a parents' group to help each other and gather information on resources throughout the state. Parents meet in small groups on a regular basis.

86. It is the purpose of the pre-school program at the Connecticut State Board of Education and Services for the Blind to provide for all visually impaired preschoolers so that they can maximize . . .

. their potential and not be left in an isolated, non-stimulating environment.

- 88. We work with parents . . .
- 89. with other professionals . . .
- 90. and with schools, to meet all . . .
- 91. the educational needs . . .
- 92. of each child.

"INSTITUTIONAL PROBLEM AREAS OF VISUALLY HANDICAPPED CHILDREN
IN THE AGE GROUP FROM BIRTH TO SEVEN AND THEIR SOLUTIONS"

Yolanda Noemi Penerini
(Buenos Aires, Argentina)

PROGRAMME: "ORIENTATION AND ATTENTION OF VISUALLY HANDICAPPED CHILDREN"

AIMS:

- To advise visually handicapped children's parents about their children's future.
- To help parents to understand ophthalmologic diagnosis.
- To allow local assistance to patients coming from distant places.
- To achieve the centralization of services to avoid relocation, loss of time, money and energy.
- To help parents stimulate their child's other senses by working with the child in front of them as a model.
- To awaken in parents feelings of responsibility towards their handicapped children.
- Encourage parents to have a responsible attitude in order to participate in the child's future.
- To help to detect visual development in some pathologies.
- To allow children to grow up at home, encouraging individuality and avoiding cultural identity loss.
- To detect the need for the creation of services, in geographical places where requests come from.
- To use the present structure of resources of the existing services, avoiding additional expense to the National Government.

POPULATION ASSISTED:

Visually handicapped children from birth to fourteen, in the Ophthalmology Service, according to the typification of "General Children's Hospital, Ricardo Gutierrez" in Buenos Aires.

Table 1. Children assisted from April, 1979 to April, 1983 (4 years).

Sex					
Male		Female		Total	
Nº	%	Nº	%	Nº	%
93	47	105	53	198	100

Table 2. Assisted children, Age at the first visit.

Ages	Nº	%
To 2 years	107	54
3-5 years	45	23
6-8 years	32	16
9-11 years	8	4
12-14 years	6	3
TOTAL	198	100

GEOGRAPHICAL AREA:

The General Children's Hospital in Buenos Aires, is a neurologic center of specialized consultation. It assists children that arrive spontaneously or that are sent by other hospitals from every part of the country and in some cases from neighboring countries.

Table 3. Assisted children : sex and area of origin.

Area	Sex		Total
	Male	Female	
I Capital Federal	11	13	24
Providence de Buenos Aires	63	52	115
Central	1	7	8
II North East Argentina	15	17	32
III North West Argentina	1	6	7
IV Cuvo	-	-	-
V Patagonia & Comahue	1	8	9
VI Neighboring Countries	1	2	3
TOTAL	93	105	198

RESOURCES:

The Programme of Orientation and Assistance of Visually Handicapped Children takes place on Thursdays. It is led by a Sociologist and Teacher of blind children (volunteer), having previous experience in Visually Handicapped Children's Adolescents', and Adults' education in specialized institutions. This professional training in Early Stimulation was performed under the instructions and teachings received from Mrs. Ana Maria Polito de Fiondella (Phonoaudiologist).

Table 4. Children with blindness and low vision.

<u>Date of admission and sex</u>			
Admission	Male	Female	Total
4/4/79 - 4/3/80	25	27	52
4/4/80 - 4/3/81	27	22	49
4/4/81 - 4/3/82	19	25	44
4/4/82 - 4/3/83	22	31	53
TOTAL	93	105	198

IDENTIFICATION:

When the diagnosis of visually handicapped is established, the Ophthalmologist sends the children to the corresponding service, to start with the appropriate treatment.

Making use of the services of the hospital and its human resources, specializing in children, reports are required from different areas as: Pediatrics, Cardiology, Psychopathology, Mental Health, Genetics, Physiatry, Otolaryngology, Neurology, Oncology, Endocrinology, etc. Co-operation with the different services is asked in order to assist all visually handicapped children utilizing a professional in each area.

The aim is to be able to consult in each area with a professional that has become familiar with certain characteristics of the visual handicap and to prevent a wrong diagnosis caused by its disregard.

To this purpose the first children were examined in front of the person responsible for the Programme.

Table 5. BLINDS:

Pathologies	Sex		Total
	Male	Female	
Retinopathy of prematurity	20	16	36
Disk atrophy	4	6	10
Leber's congenital amaurosis	5	2	7
Anophthalmos	3	4	7
Glaucoma	4	3	7
Hypoplasia of the optic nerve	4	3	7
Retinoblastoma	1	4	5
Congenital corioretinitis	1	2	3
Microphthalmia	-	3	3
Congenital cataracts	-	2	2
Peter's anomaly	1	1	2
Retinal detachment	1	-	1
Perforated corneal ulcers	1	-	1
Retinal dysplasia	1	-	1
TOTAL	46	46	92

Table 6. LOW VISION:

Pathologies	Sex		Total
	Male	Female	
Congenital cataracts	14	24	38
Atrophy of the disk	7	9	16
Retinopathy of prematurity	6	7	13
Hypoplasia of the optic nerve	5	4	9
Glaucoma	3	5	8
Iris, choroid & retina coloboma	4	3	7
Retinoblastoma	1	3	4
Corioretinitis	2	1	3
Albinism	1	1	2
Acquired cataracts	1	-	1
High myopia	1	-	1
Aniridia	1	-	1
Microcornea	-	1	1
Malformation of the disk	-	1	1
Leber's congenital amaurosis	1	-	1
TOTAL	47	59	106

THE PROGRAMME BEGINNING: Background

The observation of the real psychic damage that blind children and those with subnormal vision and their families showed, led Dr. Alberto Ciancia, chief of the Ophthalmology area of the "Children's Hospital" to ask Dr. Lydia Coriat's co-operation, in 1969. She is a Pediatric Neurologist, specializing in normal and

pathologic evolution.

Through the evaluation and systematic observation of blind children, they concluded that the damage was caused, mainly, because of the lack of stimulus in early life.

Some techniques used with babies with other pathologies, were adapted, and relevant changes in the development and maturity of visually handicapped children could be observed.

A new concept in Health, that implies "Social-Medicine", reminded us that a doctor's work goes beyond the act of curing and includes the development of the patient's potentialities.

In 1974, Dr. Ciancia asked for a sociologic investigation to determine the acceptance in the family and school environment and the general development of these children, once they left the hospital.

As a result of this investigation they decided:

- a) To choose an ophthalmologist, specializing in Children's Optical Assistance. Dr. Lydia R. I. de Gurovich, a well known ophthalmologist, specializing in Amblyopia and Low Vision, took over the task.
- b) To create a minimal team for pedagogical and social assistance in order to inform and orient parents.

In 1979, the Programme, whose results are shown in this work was started.

KIND AND DEGREE OF PARENTS' PARTICIPATION:

Children attend classes with their parents in order to work with them, in front of them and taking part in it.

The main aim of this is to prevent parents' denial of their responsibility, due to their ignorance of the treatment of visually handicapped children. When each class or session is over, some guide lines are written for continued interaction with the children at home.

They refer to the way activities of daily living skills such as washing and dressing are practical in order to achieve a better relationship with their visually handicapped child and include them in their daily activities.

Table 7. Calendary pattern of assistance

<u>Period of assistance</u>	<u>Children assisted per year</u>	<u>Days of attention per year</u>	<u>Number of appointments per day</u>
4/4/79 - 4/3/80	52	24 - 52	6
4/4/80 - 4/3/81	101	34 - 51	6
4/4/80 - 4/3/82	145	34 - 51	6
4/4/82 - 4/3/83	198	38 - 50	6

WHERE ARE CHILDREN SENT WHEN THE PROGRAMME IS OVER:

Children are sent to the educational center for Visually Handicapped Children, closest to their home.

As cases were detected in areas with no educational assistance, the corresponding authorities were advised to create the services and together with "Direccion de Escuelas Especiales de la Provincia de Buenos Aires". Four new services to extend the education to visually handicapped children were created immediately after the creation of human resources in the area.

CONCLUSIONS:

- This type of Programme can be carried out in areas with scarce resources, having ophthalmologic centers.
- The use of the existing Resources prevents additional expenses for the National Government. An agreement between the Hospital Center and the Blind Assistance Institution makes possible programme developmenmt led by a Teacher for Visually Handicapped children.
- It makes possible a better knowledge of prevalent pathologies and a permanent ophthalmological control.
- It allows to know when--at what children's age--the interest to ask for an educational guide arises in their parents.
- It makes possible to determine patterns of the general evolution in Visually Handicapped Children in order to develop an educational action specially programmed.
- It makes possible to detect needs to follow the pathology evolution and the use of the remaining vision in children with Low Vision, by the "Ophthalmology Service Staff".
- It facilitates suitable therapeutic research groups when patients have other additional pathologies preventing them to be integrated in public schools.
- The results of the Programme can be considered as highly positive, not only for the benefits to children assisted and their families, but also for the possibility it gives for access to the problems of blindness to the physician, assistant and administrative staff.
- It fosters the achievement of a better understanding of the possibilities to integrate visually handicapped children.

AN ASSESSMENT OF PRESCHOOL PROGRAMS FOR THE EDUCATION OF

VISUALLY HANDICAPPED INFANTS AGE 2 - 6

BASED ON A STUDY OF THE

NAB-MATA LACHMI NURSERY FOR THE BLIND, BOMBAY, INDIA

Banoo S. Tarapore
(India)

Ideals are usually unattainable otherwise they would not be ideals. They are the targets we set ourselves and the degree of success we achieve in pursuing our goals spurs us on to greater efforts. In the context of our present subject 'The First Steps', the efforts made by concerned agencies the world over to assimilate the visually handicapped into the mainstream of life, needs must start at the very beginning.

Importance of Preschool Education: The importance of the early years cannot be too strongly stressed. The most formative age of behavior patterns is the first five years of life, the preschool span, especially between 2 and 5 years of age. Therefore, the adjustment which the blind child, as much as a sighted one, makes in his early years, is crucial to his life.

It is at this time that enlightened parents and enlightened educators joining hands can provide the ideal environment in which such children can blossom and flower. Unfortunately this ideal, as far as my limited knowledge goes, falls far short of its potential in the developing countries where even minimal facilities for such children are not available.

In India, the overwhelming majority of blind children are to be found in remote villages or in rapidly multiplying city slums, spawned by the spreading evil of urbanisation.

In such homes, burdened with a crippling poverty, these children are unwanted additional mouths to feed. Not only are they severely undernourished but are totally neglected as well. The parents themselves illiterate, see no point in educating such a child, nor are they aware that there exist any possibilities of doing so. In this uncongenial atmosphere what sort of future is there for the child?

Compare this with the expert professional care extended to such children in a free residential nursery such as the NAB-Mata Lachmi Nursery for the Blind, Bombay, with which I am primarily concerned. I can speak from first hand knowledge about the dramatic change both physical and mental that takes place in the child after it has been with us for some time. This I feel is justification in itself for institutionalized care, given similar conditions, and overrides the more obvious disadvantages that might hold valid in happier circumstances and more favorable climates.

It does not follow from this, that preschool education for the visually impaired child is necessary only when parents are unable or unwilling to give the training and encouragement he needs. It is the first stepping stone in life for every child, sighted or otherwise. In the nursery he learns more easily and readily as part of a group sharing rights and responsibilities, he learns to communicate and socialize with others outside the family group and he grows in physical independence and self-confidence. The blind child additionally will also learn to locate auditory clues, to connect words with actions and objects and to undertake a tactile exploration of his immediate environment. "The first major step towards adjustment to the formal classroom and his future has been made".

Need for Motivation: Conceding the importance of preschool education

for the visually handicapped, the difficulty, at least with us in India, is to motivate the parents and convince them of the benefits of early education. In spite of a population of blind children said to be running into two million, the 250 institutions imparting education to the visually handicapped all over the country at the higher level, let alone the preschool one, find it difficult to get enough children to fill their benches.

The NAB-Mata Lachmi Nursery averages merely 20 children a year, the others even less. They are usually referred to us by social workers attached to hospitals where these children are brought for treatment, or by the Home Teacher appointed by the National Association for the Blind. Realizing the obvious need for wider publicity, the Nursery sent out letters to Health Officers and District of Maharashtra State requesting them to help locate such children and inform their parents about the facilities the Nursery had to offer. While cooperation from the officers was forthcoming in the form of long lists of names and addresses, the matter ended there. Either the parents were not convinced or the officers were unable to contact them.

Similarly the Education Officer of the Bombay Municipal Corporation which runs over 1200 Municipal schools serving the children of the lowest income groups, was requested to put up notices in every school, giving information about our Nursery. This also had no effect at all, possibly because we did not have the time or the resources to follow it up.

Another effort in this direction, was the commissioning of a short audio-visual presentation in color on the activities of the Nursery, for public exhibition at various centers. It has generated a little interest and should have greater impact, once the English commentary is translated into vernacular languages for exhibition in rural areas.

But paucity of funds and limited resources are ever present deterrents to any ambitious scheme. This could be obviated if a central agency such as the Department of Social Welfare in each State would set aside earmarked funds for publicity projects which would create an awareness of existing facilities for all categories of the handicapped, through various communication media, so that those concerned will come forward to avail themselves of the opportunities offered.

Existing Facilities: Unfortunately, as already stated, preschool education for the visually handicapped in India, has yet to take off. So far it exists only in the form of a special class attached to the recognized schools for the blind in urban centers, catering to a handful of children varying in ages from 5 to 10 grouped together solely because they have had no formal education before. The NAB-Mata Lachmi Nursery is the only one not attached to a school, takes in children between 2 to 5 and follows the normal Montessori course.

As for the alternative of Integrated Education, another ideal to strive for, whereby a blind child attends the nearest local school along with his sighted friends, we are indeed still a long way off. With very rare exceptions, integrated education in our country is implemented only after the VIth grade, when the children are 12 years old and above. And it is only very recently that schools in the metropolis of Bombay, which is supposed to be the most enlightened, have started even entertaining the idea of admitting a blind child.

Here again, the NAB-Mata Lachmi Nursery has pioneered an integrated education program at Nursery level which will be discussed later on.

NAB-Mata Lachmi Nursery for the Blind: Now coming to the Nursery itself, it is a joint venture of the Mata Lachmi Trust and the National Association for the Blind. In 1969 the Trust offered the free use of the third floor of its Hospital building and an initial donation to the Association, to start the Nursery with. Everything here is free and that includes residential facilities, education, meals, transport and medical treatment. Due to limited accommodations, the number of children has to be restricted to 25 at most.

Begun with just three children, today 127 children have passed out of this institution, the majority of them gaining admission in the various schools for the blind, so that in the normal course of things, each one will have studied up to the school leaving certificate stage at least. According to our ophthalmologist, Dr. Joglekar, "80% of those who come to us are blind due to congenital malformation such as Anophthalmos, Microphthalmos, or micro cornea with or without coloboma of iris and choroid etc. Another 15% is accounted for by infections in early age, generally supervening small pox and measles, causing anterior staphylo-ma and pthisis bulbi and Atrophi bulbi. The remaining 5% are due to Avitaminosis, causing total corneal opacities with or without adherence to iris. Some cases were admitted for blindness after congenital cataract surgery but the number is negligible".

To deviate a little, according to a recent survey undertaken by the Royal Commonwealth Society for the Blind, (South Asia), an estimated 42,000 children in India suffer from xerophthalmia or blinding malnutrition associated with the lack of vitamin A in childhood. The Society is launching a massive program to tackle this problem during the current year covering a population of 350,000 in 310 villages and 30 urban slum colonies in 10 states.

In our state of Maharashtra, this Society in conjunction with the NAB-Abdullah Fazalbhoy Center for eye care, also an activity of the National Association for the Blind, organizes camps in villages and slum areas where children found suffering from Vitamin A deficiency are administered a high potency dose of Vitamin A syrup which has a six months effect. The parents of these children are also instructed on the preparation of low cost, protein fortified foods from cheap easily available vegetables and cereals which are rich sources of Vitamin A, such as spinach, carrots, drumsticks, ground nuts etc.

Returning to our statistics, the overwhelming majority of our children come from very poor homes, some from lower middle class families and just a few from more affluent backgrounds. The professions of the parents range from that of domestic servants, factory workers, mill hands, watchmen, lower clerical grades, to those having their own small business like carpenters, tailors, fruit vendors etc.

Belonging as they do, to various castes and creeds, they hail from Tamil, Malayalam, Sindhi, Hindi, Gujarati, Punjabi and Marathi speaking communities.

The Language Problem: This diversity of languages poses a problem. The Nursery has adopted Marathi as the medium of instruction, as it is the recognized State language, besides being the medium of instruction in the local schools for the blind. Also the number of children is too limited to make provision for instruction in an additional language. This, however, is unacceptable to parents belonging to other communities who want their children to learn in their own mother tongue. This applies also to parents from other parts of India, who are reluctant to send their children here, as they themselves are unable to speak or follow Marathi. Similarly, those belonging to more affluent sections, want their children to be taught in English only and do not like their children to mix with those of lower income groups. This is one of the main reasons we are not getting as many children as we should. This could be resolved if narrow parochial attitudes were given up in the larger interests of the child on the one hand, and on the other by establishing a common link language such as Hindi or English, fairly well understood all over the country, as the medium of instruction in schools for the blind, all over India.

Age of Admission: Another vexing problem concerns the age of admission. The Nursery admits children between 2 and 5 years of age. But frequently they come to us at 6 or 7 without any previous educational background and even without the most elementary training in hygiene. They cannot be kept at the Nursery as

all schools stipulate that a child should not be more than 6 years of age in the 1st Standard, and at the same time refuse to accept those who have not reached a certain standard of proficiency. At most they are prepared to keep the promising cases only, in a special class attached to the school, where within the span of a year the child is expected to reach a level which he would normally have taken two or three years to attain.

Obviously all children will not find it possible to acquire the required grade in the required time. Those who are unable to cope up will be subjected to mounting pressures leading to psychological damage in the shape of inferiority complexes or anxiety neurosis and very likely will be labelled dull ever afterwards.

It would be more sensible if a child is allowed to be kept on at the nursery stage till he is 6 or even 7 and the decision to transfer him is based on an estimate of his ability to profit from education at the next step, and I believe is being done at the Sunshine Homes run by the Royal Institute for the Blind, U.K.

Program of Health Care: Once a child is admitted to the NAB-Mata Lachmi Nursery, the program of health care takes precedence over all else, for the children we get are woeful little specimens of humanity whom none else will take. In a majority of cases children even 3 or 4 years old cannot walk, or utter a syllable and often have never tasted solid food.

On admission each child is screened by a panel of doctors consisting of an ophthalmologist, a pediatrician, a psychiatrist and an ENT specialist. With conscientious follow up treatment supplemented by a nutritious diet, those children slowly gain normalcy.

Here the most remarkable results are achieved through intensive physiotherapy sessions. In this connection Mrs. S. M. Chainani, our visiting physiotherapist, says, "A child achieves many milestones due to visual input and excitatory stimulus. Deprived of these, our blind children suffer from delayed milestones like inability to crawl, sit up, stand or walk, or even from mental retardation. Since they come from impoverished backgrounds, they face acute malnutrition problems. Nutritional deficiency is an important contributing factor in mental retardation, and lack of input of visual impulses is responsible for delayed development in spite of fairly good muscle power. However, deformities and contractures can be partly corrected with corrective appliances, like light splints, braces, specialized footwear, and gait training through postural exercises. The earlier the treatment begins, better are the prospects of achieving normal patterns. We begin physiotherapeutic treatment with passive movement using proprioceptive stimulation along with vocal instructions. These progress to active assisted, and active movements. Depending upon the child's development stage, we devise exercises for muscle re-education, improvement of posture etc. We also make extensive use of equipment like the crawler, sitting box, stand-in table, tilt-table, parallel bars and wall bars. As the child progresses, we introduce exercises to improve balance and equilibrium to develop spatial orientation."

In accomplishing this process of rehabilitation, lies our triumph. From all that we have attempted, perhaps nothing is more satisfying than the minor miracles we have achieved in salvaging what seemed hopeless cases. We have laid the foundation for others to build on.

Educational Programs: Once the physical hurdles are crossed, and that could take quite some time, the child starts to learn basic skills and begins to mix with others and moves with confidence. It is ready now for the nursery routine - action songs, number work, craft, general knowledge, language and introduction to the Braille alphabet.

Integrated Education Program: For the older children, that is for the age group 4 - 6, the Nursery has a program of Integrated Education. Thrice a week

they attend Shishu Vihar, a nursery for sighted children. This is not only in keeping with modern trends which look upon segregation of the handicapped as both unfair and unnecessary, but also provides a welcome break from routine and a change of scene. At the same time, the Nursery continues to impart the specialized education which is also necessary viz. orientation, mobility, introduction to Braille, besides creating a home atmosphere where the children feel loved and cared for.

Integrated programs, however, need to be implemented with skill and imagination, otherwise the handicapped child will not really form an integrated part of the group and will tend to be more isolated and resentful. Surlatai Deodhar of Shishu Vihar Mandal says, "The idea behind integrated education mainly is to make the child feel that he is no different from other children. He realizes that he is learning and doing the same things as the rest and consequently there is no feeling of inferiority. It is our experience that this program has worked successfully."

Unfortunately, as stated earlier, the majority of educational institutions in our country are not yet ready to accept the handicapped as a matter of routine.

Program for the Multiply Handicapped: The Nursery also admits multiply handicapped children of nursery age, the deaf-blind, and the mentally retarded blind. Though they live at the Nursery, they are sent for their educational programs to specialized schools qualified to train them as the Nursery is not suitably equipped or staffed for this purpose. But such children in view of their severe restrictions make very slow progress and are not ready for transfer though well over the nursery age. Even with due concessions, they obviously cannot stay on indefinitely, as they would be blocking the place of other children who are blind but otherwise normal. But they have no other alternatives. The institutions they attend have no provision for residential facilities, without which it is impossible for them to continue their education. They end up by staying home, and relapse into their former state. We realize the futility of accepting them in the first place, but as yet can see no way out of this dilemma.

Parental Attitudes: All these different programs and activities of the Nursery, naturally presuppose whole-hearted cooperation from the parents of the children. As the late Wilma Hull, Preschool Program Supervisor at Perkins put it, "Parents should be as much a part of the preschool programs as their children. No parent is ever prepared for the advent of a blind child. Therefore, if the education of a visually impaired preschooler is to be truly effective, it should also involve the child's parents."

Children live up to what is expected of them. The family's attitude towards his disability will guide the child's own perspective. So the first step in the right direction is to educate the parents not to lay stress on the child's disability, not to make him feel different from the rest, not to be over protective or negligent either and to lend the fullest support in reinforcing at home, all that is taught in the classroom.

But here again, one falls short of the ideal. The attitude of the parents towards the child varies from total rejection, hidden rejection, refusal to accept the handicap, to a fatalistic resignation. Rarely indeed do we come across parents who show any eagerness to provide their handicapped child with the best possible opportunities. But then this is scarcely surprising considering the constant struggle they have to put up in a life beset with hardships in which the birth of such a child is regarded as an added infliction. So the Nursery tries to foster and encourage family ties whenever possible. Monthly parent-teacher meetings and counselling sessions are arranged where the parents come together to exchange information, discuss problems and seek advice. Here again, working parents find it difficult to get time off and many fight shy of revealing their

problems in front of others. The solution to this is the appointment of a full time professional social worker who would be the vital link between home and school and advise both to their mutual benefit.

The Nursery also insists on children compulsorily going home on alternate weekends and for the month long May and November holidays, so that enduring positive family relationships are forged and the children feel loved and wanted. For as one author has put it, "All children depend on parents, families and on the communities in which they live to provide a favorable atmosphere for growing into normal, healthy and happy people."

Exposure to Varied Experiences: Will these visually handicapped children grow up into socially satisfied, economically independent, physically active adults? The answer is 'yes' if given the right opportunities from the very beginning. Emphasis here must be placed on exposure to as wide and varied social contacts as possible. The child does not live in a vacuum. He is a part of the world he lives in and he must be actively aware of what is going on around him.

In this again, the nursery school experience is invaluable. Besides the mental stimulation that he gets, the child is involved in a lot of physical activity as well, such as a dip in a pool, a swing in the park, a ball game, a romp in the garden, absorbing at the same time the beneficial effects of fresh air and sunshine. In crowded cities of course one has to make do with what one has. The NAB-Mata Lachmi Nursery, though situated on the third floor of a hospital building, is fortunate in acquiring the exclusive use of an adjoining Munciple Park through the kind cooperation of the Municipal Corporation, and has suitably equipped it with play apparatus gifted by generous donors.

Besides, the children are taken out as frequently as possible. There are trips to the zoo, the National Park, the seaside. The children get swimming lessons, do yoga exercises and annually take part in organized sports for the handicapped. Once a year they are taken for a short holiday camp outside Bombay amongst sylvan surroundings. And at the end of each school year they put up a colorful costumed performance on stage which they enjoy every bit as much as their invited audience.

Much, therefore, can be done, given the initiative and the drive. The possibilities are tremendous if institutions offering facilities for preschool education of the visually handicapped could get together periodically for an exchange of ideas, a pooling of resources, an overall assessment, like the present international meet which has set such an excellent example.

For the last word, let us look upon the handicapped child primarily as any other child, in need of the same love and acceptance which is the birthright of all children. As a noted educationist said, "Treat him first as a child and only second as a blind child". Make light of his disability, praise him whenever possible and so instill in him the courage and the confidence to face a life in which he has unfortunately started off with a handicap.

IDENTIFYING CHILDREN WITH VISUAL IMPAIRMENTS -
PARENTS, NURSES, TEACHERS MAY CONTRIBUTE TO THE
ASSESSMENT OF VISUAL FUNCTIONS

Eva Lindstedt
 (Sweden)

The behavior of the sighted child is to a great extent initiated and guided by vision. By observing the behavior we may get information of how well or bad vision is functioning. This is simple knowledge applied by every parent, nurse and doctor, more or less consciously.

When it comes to assessing the degree of a presumed low vision, doctors and nurses seem to distrust behavioristic methods. They want more exact and scientifically reliable methods to found their opinion, particularly when they are to inform the parents of the child's visual impairment.

The current methods of assessing vision, e.g. visual acuity and binocular vision, as a rule are very inappropriate for use in infants and small children below the age of 2.5 years. We know now that at this age the visual development has already reached its peak and the sensitive periods are passed to a great extent. If our goal is to influence visual development, we would be too late if postponing treatment until current methods are applicable. For multiply handicapped children such methods may be totally out of the question.

In the infant and toddler, the behavioristic methods are the ones we have to use. The bad reputation of these kind of methods, i.e. measuring visual functions by observing a child's behavior, is very unjust. They may be very reliable indeed, which e.g. is shown by the many reports recently published concerning studies of vision in infants using PL-technique (preferential looking).

Doctors and nurses have to acquaint themselves with such methods, learning their possible usefulness and reliability. They will find that these methods are good if used systematically and standardized as far as possible. They may certainly enable the doctor or nurse to assess the level of visual functioning of the child, thus giving the parents and teachers guidance as to the relevant program of visual stimulation.

(See Figure 1)

The visual behavior is an activity resulting from complex psychomotor processes reflecting also the child's total mental, emotional, sensory and motor capability. If the visual development seems retarded, assessed by observation of the behavior, it may be difficult to conclude on which link in the psychomotor pattern is "at fault".

To make a good assessment, the observer needs a lot of knowledge; knowledge of the earlier visual development, of the sensitive periods of different visual functions as well as of the mutual dependence that exists between the sensory, emotional and motor stimulation and activity on one hand and the development of vision and general development of the child on the other. In the Reynell-Zinkin Scales reported on by several speakers of this seminar, we have another tool to help the professionals.

For the doctor or nurse this knowledge is necessary but not enough. To draw the best conclusions, they have to rely not only on their own observations but to look after and utilize the observation of those living close to the child.

Parents are very good observers of their own child. Their ability to interpret their observations naturally are limited as they lack scientific and medical knowledge. The doctor or nurse may help in sorting out relevant observations. The first step is then for doctors and nurses to listen to parents, to

encourage parents in observing their child and to teach parents what to observe, sorting out typical behavior for which vision is crucial.

Unfortunately, parents very often feel that doctors and nurses do not listen to them and distrust their observations.

Mary Sheridan has given very good descriptions of the development of visual behavior of the normal, sighted child. Considering this knowledge, adding information of recent research, we may pick out a few relevant visual behavioral traits that may be observed. More or less evident divergency from normal thus may be traced early.

(See Figure 2)

If the parents suspect a delay of visual development, they may particularly observe some of the listed behavior/performances of the child, noticing if the behavior is there at the expected age or not, if it is developing at a later age a.s.o.

(See Figure 3)

(See Figure 4)

The information derived from such observation may be considerably more useful if the visual objects are graded and the visual sphere noticed as well.

Abnormal oculomotor signs give important information and sometimes are the only available evidence signifying low vision in a baby.

It is to be pointed out that a divergency from the normal, e.g. of the fixation capability, does not exclude that development may start later.

The development in low vision children and multiply handicapped children may be considerably delayed, e.g. a child who does not fixate during the first weeks of life may begin to do so during the second or third month. There seems to be a delay also of the sensitive periods, which means that stimulation may be successful for a prolonged time, although the progress may be very slow. The type of stimulation should be adjusted to the developmental maturation of the visual system.

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LEVEL OF VISUAL FUNCTIONING/PERFORMANCE

LEVEL	VISUAL PERFORMANCE	VISUAL SPHERE	VISUAL ACUITY	NOTES
I	Recognizes faces at near. Big toys. Mobility difficult (visually guided). As a rule not ball-games.	0,5-1 m	0,01-0,05	May be performed by peripheral vision without steady fixation. Contrast sensitivity has to be fairly good.
II	Rather small toys. "Looking-near" behavior Mobility/orientation fairly normal. Riding a bicycle may be possible. Sometimes ball-games.	3-4 m	0,05-0,1	Some fixation capability is necessary.
III	Mobility/orientation normal. Very small toys objects Details in pictures. "Looking-near-behavior" is a rule	good, but no details at far	0,15-0,3	Fixation and accommodation is required.
IV	Ordinary text may be read without difficulties	normal	0,3	If there are defects of contrast sensitivity or oculomotor functions, visual problems may occur. (1)

(1) Visual field defects may influence the visual performance negatively, regardless of the level of visual function.
Abnormal dark adaptation or light adaptation will also augment the actual visual handicap.

FIGURE 1

LIST OF NORMAL VISUAL BEHAVIOR
DURING THE FIRST YEAR OF LIFE

Newborn	Turning head towards window or other diffuse light. Fixation of visual objects. Following visual objects.
around 2 months	Turning head and gaze towards visual objects. Eye contact, emotional response on faces.
around 3 months	Emotional response on visual objects. Looking at his own hands, playing with them. Visually directed reaching for objects.
around 4 months	Turning head and gaze, looking at a sound source (hearing children).
6-10 months	Attentive visual investigation of objects, picking them up, moving them close to the eyes. Crawling towards visual objects, avoiding obstacles.

FIGURE 2

VISUAL BEHAVIOR - A CHECK LIST

	Normally	Child
Fixation of light	newborn	
Fixation and tracking of objects at near (0,5 m)	newborn - 4 weeks	
-"- at a distance (≤ 2 m)	2-3 months	
Eye contact	4-7 weeks	
Playing with its own hands in front of the eyes	2-3 months	
Directed reaching for objects	2-4 months	
Attentive visual investigation of objects at near	6-10 months	
Directed mobility towards objects, avoiding obstacles	6-10 months	

FIGURE 3

MATURATION OF OCULOMOTOR CAPABILITIES

	Normally	Child
Steady fixation	newborn	
Smooth movements, tracking scanning	1-2 months	
Accommodation	1-3 months	
Convergence	1 month	
Concomitant binocular movements	1-3 months	

Abnormal

Lacking or instable fixation

Rolling eye movements

Jerky, slow, unprecise horizontal movements

Failing tracking

Nystagmus

Squint

Abnormal direction of gaze (when fixating)

FIGURE 4

A RETROSPECTIVE LOOK AT PRESCHOOL VISION SCREENING

IN A RURAL REGION

Wanda J. Thompson
(U.S.A.)

Thirteen years ago this writer entered the world of preschool vision screening. Money had been made available for handicapped children under Title VI of the Elementary and Secondary Education Act. In Illinois, thirteen regional programs were established throughout the state and a large portion of Title VI money was used to develop vision and hearing screening programs.

The Title VI project based in Decatur was just over a year old when I was hired. Up to that point the staff included a director, a nurse, six technicians, and a secretary. The nurse set up and supervised the screenings. The technicians worked part-time and primarily did vision screening. Hearing screening was done by audiology students from the University of Illinois. I was employed on a part-time basis to follow-up on the children referred by the screening program.

It is often said that most people don't choose their careers, they just happen into them. So it was with me. My son was about six weeks old and I was looking for work part-time, preferably with children. A classmate of mine from nurse's training called to say she had just the job for me. She was the nurse setting up and supervising the screenings, and she said they needed someone to follow up on the screening referrals --- was I interested? "Why not?", I thought. They could only promise me four months of work, but I was not interested in making much more of a commitment than that myself. I didn't know how working would combine with motherhood.

I started work on April 8, 1970, was given a couple days of orientation, and was scheduled to accompany the team to a screening about thirty-five miles from home. I should point out that all I knew about vision screening at that stage of the game was people were supposed to have two eyes. Nurses were not routinely taught to do vision screening. The morning of my first screening I awoke to a spring blizzard, and we couldn't get out of town. The screening was cancelled and then we all watched in dismay as the snow stopped falling, the sun came out, and by noon it looked like a typical spring day. The snow was completely melted. Such was my welcome to the world of vision screening. First big lesson: don't trust the weather.

Over the years I have worked every possible aspect of vision screening. My friend left in 1971 to have a baby, and I took over her job as well as my own. I set up screenings, supervised technicians, followed up on referrals, and when need be, I also screened. There were no guides, no manuals, no "how to" books on screening. Preschool children were screened in mass community screenings, in day care centers, and in nursery schools. We also screened elementary schools when there were no school nurses to do the screening. The Illinois Department of Public Health was just developing its courses to train technicians to screen. Child find programs in our area were in their infancy.

In 1972, the Illinois Department of Public Health took over the administration of vision and hearing screening programs, and the Illinois legislature mandated special education programs for all handicapped children ages three to twenty-one. Our agency then began developmental screening programs and have now evolved into birth to three screening programs. These programs have always included vision and hearing screening, however, through interagency agreements.

I would now like to briefly acquaint you with the make up of my region and then I will discuss the "how to" of screening programs; all the points I

learned the hard way.

The region I travel encompasses fourteen counties, 8,489 square miles. Four counties are predominately urban, ten are predominately rural. There are two metropolitan areas with a population over 100,000. Three areas are over 20,000. The majority of the towns are very small, many less than 10,000 people.

Most of the people are white (72.9%). The majority of the non-white population is black and is located in the large metropolitan areas. One county has a community of Mexican-American migrant workers. Another county has a large Amish population. The Mexican-American children usually speak Spanish as their primary language. The Amish children often speak German.

The roadways covering those fourteen counties vary greatly. There are four lane interstate expressways, two lane highways, gravel roads, and "slabs" (one lane paved with gravel shoulders). In the winter we dodge "pot holes" in the road, in the summer we dodge the construction crews filling the "pot holes".

Temperatures in east central Illinois range from sub-zero in the winter to 100° plus in the summer. Agriculture is one of the largest industries with corn and soybeans being the major crops.

No matter where one screens or who one screens there are nine areas one must address for a screening program to be successful. These are the nine P's of screening (Illinois Department of Public Health, 1982): Planning, Politics, Population, Personnel, Preparation, Place, Permission, Procedure, and Paperwork.

Planning

This is your master plan. It should include your objectives, your activities, your methods in the sequence you plan on doing them. It should also include your evaluation plan. You may want to form a committee to help develop the plan. Be sure to allow enough time to develop and publicize your program. I always start with the targeted screening date and work backwards in my plan. If you are developing a screening program in a new area, you may want to start as much as six months ahead so you can do an adequate job of community education. Once you have a program established it shouldn't take more than six weeks to set up the screening year after year. If you don't have a committee to help you plan, use your co-workers or your boss as a sounding board. Think of every possible problem that could arise, every question you could be asked. What will you say if a school superintendent says, "You don't need to screen my schools; there are no visually impaired children here."?

When you are planning your evaluation, you may want to consider looking at the six factors or characteristics of health care system performance since vision screening is a part of the health care system. These points which can help you measure your effectiveness include:

Availability - "a measure of the appropriate supply and mix of health services and the capacity of resources for providing care" (State Health Plan, 1980, p. 4). For example, what proportion of your capacity is being utilized? Are you screening 20 children when you could be screening 50? How can you improve this number? Equity of care should be considered as well. Do all children have an opportunity to be screened - or just certain groups?

Accessibility - "a measure of the degree to which the system inhibits or facilitates the ability of an individual or group to gain entry and receive appropriate services, including geographic, architectural, transportation, social, time and financial consideration" (State Health Plan, 1980, p. 115). Measurable examples include the distance a family must travel to the screening, how long they must wait to be seen, what kinds of transportation are available.

How easy can you make it for the family to get to the screening? We tried to hold screenings in each small town and work through a local service club or school group for transportation to make the screening as accessible as possible. Week-ends and evenings should also be considered for screening times.

Acceptability - "an individual's (or group's) overall assessment of the care available to him or her in terms of such factors as cost, quality, outcome, convenience of care, and provider attitudes" (State Health Plan, 1980, p. 115). This section of the evaluation can be measured by randomly surveying the parents or other community members to determine their satisfaction (or dissatisfaction) with many aspects of the programs. The acceptance of the program by the community will contribute significantly to its success.

Cost - how much does it cost to operate the program in total and per child screened?

Continuity - "a measure of the degree of effective linkages and coordination in providing a succession of services over time regardless of whether care is provided in one setting or in multiple settings" (State Health Plan, 1980, p. 123). More simply put, how many or what percent of the children referred for further assessment actually receive that care? How many of the children eligible for special education services receive those services? What is the continuum of care and is it working?

Quality - "a measure of the degree to which the services provided, regardless of by whom or in what setting provided resemble satisfactory delivery of services as defined by health professionals." Included in quality are the appropriate certification of both people and facilities, the use of the proper instruments and procedures, and an improvement in the overall conditions (numbers of children identified and receiving treatment).

All six factors can easily be written as measurable goals. An increased level of any of the variables except cost is good. Costs should decrease. Your evaluation is perhaps the most important part of your plan because it will demonstrate the good you are doing, the need for continuance, and where changes need to be made.

Politics

This is not governmental politics but at times it seems like it. This section looks at protocol. Who should you talk to first, who are key leaders or influential people in the community? Identify those leaders. Do parents need to be involved? How about teachers, or physicians? Are there other agencies with similar goals? It takes longer when you involve multiple disciplines, but the end result will be a much better screening program.

Interagency and interdisciplinary collaboration is at best difficult but it is essential to all child find programs. This collaboration can make your program or break it. "For professionals to interact in a truly collaborative manner, the elements of trust, respect, and mutual dependence must be present." (Magrob and Schmidt, 1980, p. 17.) It takes time to develop these relationships. Plan for that time.

Population

Define your target group. Are you going to screen preschool children, school age children or other groups of children? Will you screen certain ages

or grade levels only, or will you be receptive to referrals from others? Are there any unusual characteristics in any of your groups that will require modifications in your screening programs? As was previously mentioned, we have two such groups in our region: Mexican-American children who speak Spanish and Amish children who speak German. We tried using interpreters but found that the majority of the children could be screened most easily by pointing to matching pictures, thus eliminating the need to speak. Another problem which arose in setting up the screening program for the Amish children was a lack of electricity. As part of their religious beliefs, the Amish do not have electricity in their homes or schools. They are, however, quite receptive to health screening programs and follow through with referrals. Arrangements were made for the children to be transported to a Mennonite school nearby which did have electricity. If you require electricity, don't assume it will be available, ask about it. If it is not available, how would you adapt your program?

Personnel

Who is going to do what? Are you going to use nurses or technicians or volunteers? How are you going to use them? Who will actually do the screening and how should they be trained? How can you use volunteers? They can fill many roles and greatly reduce the costs of your program. Who will interpret the results of the screening to the parents? Who will follow up on referrals? We used technicians to do the screening, nurses to interpret the results and make referrals (medical and educational), and volunteers to help with publicity, schedule appointments, register children, and help with the general operation of the screening.

Preparation

Publicity is a big part of preparation and it needs to be started long before the screening date. Choose your screening dates carefully. Try to select dates that will not conflict with other activities. We quickly learned that screening programs in farming communities at the peak of planting time and harvesting time would have a poor attendance. We also learned to not schedule screenings more than fifty miles from home in the winter (January or February) because the weather could turn snowy or icy so quickly. Alternate dates were also planned in those months to allow for one cancellation due to weather.

Community education is a part of preparation. Parents need to be taught why vision screening is important and that young children can be screened. Many parents believe their children cannot be screened until they can read. The importance of the early identification of amblyopia cannot be stressed enough.

Use all available means of publicity. The most effective means seem to be TV, radio and notices sent home from school with older children. Be careful to keep your printed material simple and short. Most people do not read as their primary source of gaining information so all your beautiful publicity flyers may be worthless in the end. Ask the people coming to your screening how they learned about the program. They will tell you the most effective means of publicity for your area. Some churches will announce the screening in their church newsletter or during the Sunday service. Be creative, where do the people in your community congregate?

Place

Where are you going to screen, how much space do you require, is your location easy to find, easy to get in to? If you are using the HOTV Instaline device, you will need ten feet of space. If you are using the Michigan Jr.

Screening, you will need twenty feet. The Titmus does not require any distance. Where will you register people? It's nice if you have two rooms available: one to register, one to test.

Do you have money in your budget to rent a place or do you need to solicit free locations? We have used a lot of churches over the years. They are usually free and have plenty of space and plenty of electrical outlets.

It is also wise to consider the reaction of the community to your screening site. Will they accept it? When we screened the Spanish speaking children we used the church housing the children's day care program. It was a small Catholic church and the only place we could find to set up the Michigan Jr. Screener was in the main sanctuary. It had twenty unobstructed feet of space, an outlet, and was private. The only problem was we had to set the screener on the altar under the crucifix. This disturbed and distracted the children tremendously. Finally, we asked the priest to talk to the children and assure them everything was alright so we could continue with the screening.

As a final consideration, remember that you may have sick children coming into your screening exposing well children to whatever they have. Try to arrange your screening to allow for as much privacy as is reasonably possible. For instance, don't schedule more appointments than you can handle. I don't believe anyone should have to wait more than five minutes. Many preschool screenings are done in the elementary schools nowadays. It gives the school visibility in the community and just seems like a nice idea. It also exposes all the preschoolers to whatever illness the grade school children are experiencing. A couple of years ago we were screening children ages birth to five in a small rural community near Decatur. We were using the grade school and it was a beautiful facility. About ten o'clock in the morning the school secretary came in and asked if I was a nurse. "Yes," I replied. She then asked me to look at five children she had in her office. She thought they were breaking out with chicken pox. She was right! All the preschoolers we saw that day may have been unnecessarily exposed. This could have been prevented if we had used a church or other community building.

Permission

Parent permission to test the children is a must. It is very easy to obtain if the parents bring the child to the screening. If you are testing a day care center, however, you will need to send permission forms home. There are two types of permission letters: positive and negative. A positive permission requires a parent's signature. A negative permission form says, "We will screen your child unless you tell us you don't want him tested." Obviously, the negative permission letter is the easiest to use, but I'm not sure it is a true permission. I prefer the positive form.

Procedure

Vision screening usually takes less than five minutes per child even if the technician has to teach them the "game". Having a volunteer teach the children first speeds up the process considerably. In Illinois, the specific procedure for screening, rescreening, and referral is spelled out by the Illinois Department of Public Health. I am not going to discuss that procedure other than to say you can obtain a vision screening manual from Mr. Keith Rowley, Illinois Department of Public Health, 535 West Jefferson, Springfield, IL 62761.

Paperwork

First of all let me say "I hate paperwork". I try to keep it as brief as possible. It is important to keep accurate records though to not only evaluate your program but also to guide you in program modifications. Your report should reflect the number of children screened, rescreened, and referred. It should also document the number of referrals with confirmed vision problems as well as those who had normal vision when tested by an eye specialist. This will measure your accuracy. Keep records of how much time was spent in the various aspects of screening and how much it cost. I refer you back to the six aspects of health care system performance to guide you in your paperwork.

I'm sure by now my time is up. I would like to summarize by saying that preschool vision screening is an important valuable service. We have come a long way in Illinois in thirteen years. Working in screening programs is never dull. Each child is a special person, each screening program different from the rest. The hours can at times be very demanding and the miles traveled very long. I have seen many sunrises and sunsets. I have also closely observed the changing of the seasons: the first corn to sprout in the spring, the road construction and grass mowing of summer, the falling leaves, crop harvesting and migrating geese of fall, and the beautiful snow sculptures of winter. I love working in and with screening programs. Each one is a challenge, each one has its rewards. Thank you.

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A CORRESPONDENCE COURSE FOR PARENTS
OF PRESCHOOL VISUALLY HANDICAPPED CHILDREN
A CRITICAL AND PRACTICAL EXAMINATION

Ralph L. Peabody
 (U.S.A.)

Frequently one hears conferences described as meetings where persons sit around re-inventing the wheel. I have no intention of inventing or re-inventing any wheels today. Nor, hopefully will our time be spent spinning our wheels.

I believe circumstances dictate that the time has come when we must address some alternatives to the traditional ways we have been providing services, without sacrificing quality or integrity. This is not a proposal of a new idea. A number of years ago I recall Dr. Josephine Taylor discussing the idea of correspondence programs for families of preschool visually handicapped children.

I am also aware a small group discussed this at the American Printing House annual meeting a couple of years ago. It is my understanding such a course was developed a few years ago. If so, I have been unable to locate it. And of course you are all familiar with the "John Tracey Clinic Correspondence Learning Program for Parents of Preschool Deaf-Blind Children". So, if I am not proposing a new idea, why am I here?

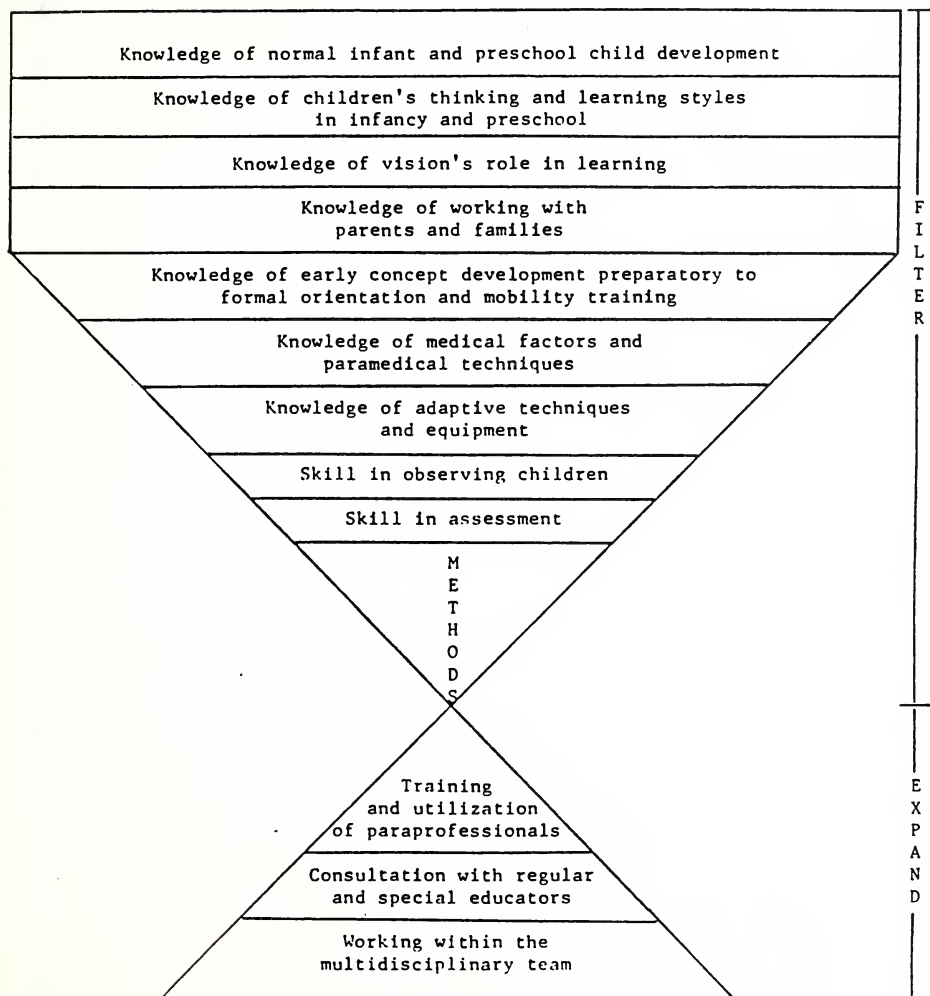
I believe this group provides the perfect arena for collectively examining this topic. We have here among us potential consumers from poverty areas, countries considered less developed, teachers working in urban ghettos and sparsely populated areas. Together we may be able to start a process to determine appropriate goals for the future.

Now, as you may be aware, I have the title of Professor. I mention this as a man by the name of Hughes, in 1965, pointed out that originally "profession or professor" referred to the act of professing. These persons profess to know better than others the nature of certain matters, and to know better than their clients what ails them or their affairs. If this were true, I would not today be seeking your thoughts and suggesting questions which may merit our attention.

I feel it necessary to state that I am not proposing correspondence programs where direct service is possible. But as you and I both know, direct service is not always a possibility, and even when it is, supplementary materials are often needed, and could conceivably be offered through a correspondence medium.

In the 1982 Position Paper written by the participants of the VIIth International Seminar on Preschool Blind and Visually Impaired Children, two sentences were included which I would like to repeat. First, "An intervention program that emphasizes the teaching of parents to teach their child must be provided to facilitate this process of learning through all sources of sensory impact." Second sentence, "Educational services may be provided in the home, day schools, centers, residential schools, or in any combination of these settings." I would like to parenthetically add we also provide a great deal of service by telephone. These are the same goals as might apply to a correspondence program. We can now start formulating some questions dealing with objectives, content, procedures, and evaluation or monitoring. Show overhead #1 (overhead on next page)

SYNTHESIS OF COMPETENCIES FOR TEACHING VISUALLY HANDICAPPED INFANTS AND PRESCHOOL CHILDREN



Source: VI International Seminar on Preschool Blind Children,
Austin, Texas, March 17-20, 1980

Other than those two statements I have just read, I would like us to do a little free wheeling with our thinking rather than formalize objectives at this time. Yet, I do feel we need a framework to guide us, as we look at the other areas. My first question then is, "What needs to be considered as a framework in discussing a correspondence program?" Remember, I promised you no wheels. Rather, I found a very concise statement which will serve our purposes. It was prepared by that position paper writing group in 1982 at the VIII International Seminar on Pre-School Blind Children.

Although developed for professional preparation of teachers, we are discussing a teaching program so all of these areas are or should be necessary components, of the content of the program.

These are questions we might ask in terms of this synthesis and content. Why is knowledge of normal infant and preschool child development necessary? Why is knowledge of children's thinking and learning styles in infancy and pre-school important? Why is it important to have a knowledge of vision's role in learning and a knowledge of adaptive techniques and equipment?

I think the answers to these questions are obvious. We have probably all known too many teachers who have been able, after much effort, to "teach" a child to string beads without knowing the necessary antecedent behavior or what to teach after that skill was learned. So the child is still stringing beads. This same teacher in all likelihood didn't select the color of the beads with the child's vision in mind or know of the availability of textured beads if they would have been more appropriate to the objectives of the task.

Two of the competencies I would like to alter slightly. I believe concept development should not be limited in scope to pre-orientation and mobility training, but development of all concepts is necessary. Also, because I am using this synthesis out of context from a much larger document, I would like to not consider the phrase "and paramedical techniques" but emphasize knowledge of all medical factors, not just those related to the eye or visual processes.

The knowledge of working with parents and families is crucial to the very concept of a correspondence program. We know from research and personal clinical experiences that they want and request information. From these previous competencies we will have the information they need and want. Our problem will be the selection of the information and its delivery in a constructive and meaningful manner. This we shall discuss when we get to procedures. Of concern also is our skills in observing children which cannot be eliminated just because our major contact is by correspondence. This may require us to change our techniques and tools.

I liked the competency "Skill in Assessment" without limiting its scope. Assessment of the child is but one factor among many to determine the feasibility of a correspondence program even before considering its content. We shall have to assess the parents and families. Are they literate? For what types of teaching would they be competent? Can they communicate with us in planning the child's program? We must know to a certain degree their financial capabilities in providing equipment as well as some preferred experiences for the child. We must have a sense of the cultural milieu to effectively select appropriate curricula and assessment instruments. We have all known parents who could not handle a correspondence program, yet others who would be superb. We must have data to determine the effectiveness or even the projected effectiveness of the parent prior to initiating such a program.

We must also assess the learning environment and monitor it in absentia. Will we have to suggest modifications? I recall an instance not very long ago where the young mother was a product of, for lack of a better descriptor, the noise age. In a very small apartment the stereo and TV were on continuously, with the baby placed between them. It took weeks to finally get the mother to understand the noise masked out important family and environment information.

Can we monitor a situation such as this in correspondence teaching?

We may need to assess the community to determine what resources and services are available to the parents as well as the child.

Now that we have identified some of the essential attributes of such a program, possibly if we now move to the procedures we can determine whether or not a correspondence program is feasible. The knowledges we have just discussed can in part serve as the criteria for the selection of a curriculum for a specific child.

We have available to us in the United States a number of published curricula. These include, among others, Vision Up (or Guide), Oregon Project, The Infant Stimulation Kit and Guidelines, and The Peabody Mobility Kit and Alive....Aware....A Person. To a greater or lesser degree these have been developed, utilizing:

- Knowledge of Normal Infant and PreSchool Development
- Knowledge of children's thinking and learning styles
- Knowledge of early concept development
- Knowledge of adaptive techniques and equipment

Therefore, I propose for some children these published curricula may in part or in combination be appropriate. For whom may it not be appropriate? When I was discussing the section on skills in assessment I mentioned such things as cultural milieu. The curricula I have just mentioned are not culture free. They very much teach skills necessary to U.S. society. But can we as a total group pool experiences with those nations in which we know these are not appropriate, and review their resources, and if there are not comparable types of programs, use the presently published materials as guidelines for others.

For some time, I have been reviewing various published curricula from the point of view of its potential use in a correspondence format. I am completely convinced, based on my own clinical impressions we have appropriate curricula for the child and need not sit down and write a new one. What we need to do is collect data on the uses of our present programs in a correspondence format to determine several factors. As a trial basis, I suggest present services might be supplemented with some correspondence lessons. Then start to collect some data. Record some specific lessons, say from the Oregon Project or Vision Up, or whatever worked? Were modifications necessary? How was it evaluated? In what environment did it take place? Was the parent or some other person the teacher? If not the parent, why not? I do not foresee curricula or lessons to accomplish certain goals as a major problem to us. Our problem lies in selection for specific circumstances.

As I look at many materials developed for parents, I see a range of sophistication from rather simple recipe books to multi-media programs. There are materials developed for parents to work with professionals and to keep developmental and medical records. There are materials to help parents budget time as well as those for developing behavior management techniques.

Now, herein lies our problems. How do we assess the situation to determine which of these materials a parent might need? I would like to propose an assumption. That is to recognize and accept the fact that in the large majority of instances, the parent's intuition is appropriate to the child's needs. If we can believe this and not profess to always knowing what's best, we can through "observation" (I shall return to this later), determine means of assisting the parent to improve upon or learn new skills.

Of course, in our early assessment of the situation or from information received we determine that no family members can handle this additional burden of teaching, we may have to further assess the community to learn more about its resources. I fully realize that in many of the countries you represent, you do not have the long tradition of volunteer service which we have in my country. Yet this might hold some possibilities for service from other than family members.

I would rely on others who may have more knowledge of the area to assist in finding suitable personnel. Itinerant public health nurses, religious leaders, and of course teachers may help to identify some human resources. If persons can be identified, then we must determine their training needs and in what capacities might they best function.

A few moments ago I used the term which was one of the competencies which was previously listed, "observation". You may also recall my first overhead transparency which, following the term evaluation, I parenthetically added the word monitoring. I believe these three functions or competencies are interdependent upon each other. I further believe any success of our efforts may well be contingent upon the manner in which we can effectively practice these competencies.

Can we observe, evaluate, and monitor the child's development, the parents' participation, the learning environment in absentia? In some situations might it be feasible to use human volunteer resources. Could we consider other alternatives. Do the parents or other instructional person have access to a telephone or radio? After initial assessment can we "observe" lessons via tape recorder? Or would the tape recorder be stolen minutes after placing it in a home, so that it might have to be kept elsewhere?

Consider with me for a moment the possible use of a tape recorder. If I have baseline information, I can select some lessons from my published curriculum, which may have high success for the parent/instructor and child. By presenting the lessons I have chosen, their modifications, materials needed, etc. by tape and by written form. I believe the voice contact might produce a better working relationship. In turn I want taped samples of the teaching situation. From these I may be able to ascertain the level of understanding the parent has of my directions. I would know if the environment is auditorially distracting. But very important I can monitor through this means the actual instructional operation. Is the instructor using an appropriate vocabulary? Are the reinforcers immediate and appear to be meaningful to the child? What are the child's reactions. From clinical experience I can possibly determine the appropriateness of the lesson and alter the assignment if it is too difficult or too simple. Of great importance, I can analyse the quality of teaching. Possibly I will have to draw from the materials for parents I previously mentioned to help the parent with timing, developing positive responses, and understanding some behavior management techniques. Very important to me is that I am becoming aware of the parent and can help them find pleasure and satisfaction in what they are doing and provide them with a little reinforcement as we develop a working relationship.

Now, it is time to wheel and deal. I have merely scratched the surface with problems which might be encountered through a correspondence program. I know many, many family constellations, idiosyncrasies of the child, environmental conditions, that to even remotely suggest such a program would be an absurdity.

Yet, we each know such a course may be a necessity in some instances. I now ask each of you for an open mind. Experiment, record your successes and problems, then share them. Together we may add a new dimension to our profession. Thank you.

THE VISUALLY HANDICAPPED CHILD:

EARLY INTERVENTION IN DEVELOPING COMMUNITIES

Theo Pauw
(South Africa)

1. WHY EARLY INTERVENTION? A SOCIO-PEDAGOGIC APPROACH

In all work with handicapped children, the need for early intervention has become axiomatic. The handicapped child is delayed or jeopardized not only in respect of the direct effects of a specific deprivation, e.g. that of vision, but in overall development and growth towards adulthood. Few parents, if any, find themselves prepared and equipped to deal adequately with the unusual demands made by a child with special developmental and educational needs. Even in the most advanced societies, these parents need all the support that can be given because few are sufficiently informed on the real nature and the full implication of their child's condition; all are likely to be alarmed, anxious and bewildered when discovering that they have an exceptional child and no one sets out on this road in possession of all the factual information that will in due course be found necessary.

If this is broadly accepted, it is conceivable that similar reactions and similar needs will become apparent in the hearts and minds of parents who form part of a less sophisticated society, whose general awareness of the current advances of science and medicine is possibly very vague or completely lacking; whose socio-economic living conditions do not place them within easy reach of such supportive services as may be available to them; and who may be further hampered by cultural inhibitions relating to factors such as family tradition, superstition, social modesty, fear of the unknown, resistance to alien involvement, and the poverty syndrome.

The handicapped child, whether situated in one culture or in another, needs special understanding and early exposure to structured and unstructured conditions and procedures that are planned to stimulate the sensory development and the experiences basic to normal growth. It goes without saying that appropriate medical, ophthalmological and pediatric treatment is essential to minimize the negative effects of handicapping conditions and to promote optimum general health in the infant and young child. Unfortunately these things cannot be taken for granted all over the world, and many children are hampered in their development on account of unhygienic home conditions, poor general health, malnutrition and lack of suitable sensory and mobility experience.

One of the main reasons for early intervention is associated with the need for suitable and sufficient stimulation of the blind or partially sighted child in infancy and early childhood. Education is based on adequate development of the child's potential, and the cultivation of this potential is thwarted by lack of experience as a result of both the handicap and the social environment. Whatever intervention is planned must therefore have a sound socio-pedagogic basis: appreciation of the special educational needs of the child and of the social factors militating against the satisfactory provision and assimilation of what is needed.

2. IDENTIFYING NEEDS IN DEVELOPING COMMUNITIES

The fundamental human aspects of coping with a handicapped child are much the same wherever the problem arises, but the emotional reactions of parents

and their possible response to help is likely to vary from one culture to another as it varies from one family to another in the same kind of community. Emotional reactions may be overt or suppressed according to individual personalities and circumstances, but also on account of cultural taboos. These factors must be known and understood by the person or the agency offering support. Whereas some studies have been conducted on public and family attitudes towards blind persons and blindness in Western Industrialized societies, the field for research is still wide open in respect of this phenomenon in developing communities. How to deal with emotive issues, particularly when alien involvement is seen as interference in very personal family matters affecting relations with matriarchal or patriarchal authority or even with ancestral spirits is often very difficult to resolve.

Let there be no under-estimation that in the assessment of this problem, even in developing communities that are already becoming gradually urbanized and industrialized. More often than not a serious dualism of personal and social values arises, the traditional values remaining a powerful force under the external guise of acquired life-styles and sophistication.

Bearing this in mind, the prospective counsellor needs to approach the subjects very cautiously, taking ample time to instill confidence and obtain rapport. He should know with whom the initial contacts should be made. (The person in authority might be the grandmother, and not one of the parents.) He may have to overcome much personal reserve, distrust and possibly a fatalistic resignation, before proceeding, and this is likely to require both time and tact.

Having done this, the counsellor needs insight into the family situation and the social environment in discussing the needs of the handicapped child; his improved prospects for development if given the benefits of early health care, medical treatment and sensory stimulation; and the reasons for wanting to attain the optimum development in spite of a handicap. (Thousands of non-handicapped children may for instance still be going without formal education and equal numbers of adults may be unemployed, in a particular country).

Then follows the imparting of information on sources of help, but not merely by reference. Representatives of the helping agencies should be personally introduced to the family, by bringing parent and child to the agency. The counsellor or an assistant, appropriately and timeously introduced, will need to organize appointments and possibly undertake or arrange transport. His personal involvement is of crucial importance, since he is by this time a trusted person and should not simply hand over administratively to other individuals without helping the family to establish the new relationships that are necessary.

Information and advice should cover essential knowledge about the child, its handicap, its special needs; about the following facilities and how to use them: health services, social services; assessment units; educational agencies, referral procedures. All this may have to be spelled out very simply and in language within the grasp of the clients. One needs to remember that too much detail and sophistication is likely to bewilder and confuse. If the parents (more usually the mother) have accepted the good faith of the counsellor, they will rely less on trying to understand technicalities than on the ability of their new friend in need to sort matters out for them.

3. MEETING THE NEEDS: INHIBITING FACTORS

If the service agency is oriented along the customary approaches, principles and practices of industrialized society, different emphases and modes of action may be indicated in applying these principles to intervention in developing communities.

3.1 CULTURAL RESISTANCE:

Cultural resistance may not be outspoken and visible, but rather implicit, passive and non-committal, resulting in lack of cooperation. It may sometimes be ascribed to inexperience and ignorance; sometimes to the inhibition of traditional beliefs and customs; sometimes to popular prejudices or superstition, amongst others the fear of retribution by the spirits of the forefathers or of other unseen powers; or possibly fear of the witch doctor, whose domain is placed in jeopardy by the involvement of persons or parties foreign to the culture. Also, the mere fact that the proposed intervention procedures represent to the family an unknown world with which they are expected to identify, a world far removed from their own life-style, for some an interrupted existence of resignation and laissez faire. It should be pointed out that these phenomena do not apply only to semi-primitive or very simple rural cultures, but in a larger or smaller measure also to various sub-cultures that are to be found in growing urban communities all over the world. Immigration and the influx of rural populations to the cities both produce conditions conducive to the creation of the kind of problems mentioned above.

3.2 SOCIO-ECONOMIC DETERRENTS

The societies referred to in this context are largely poverty-stricken and not naturally concerned with the refinements of higher living conditions. The quality of life is often such that basic survival is all that matters, and it is not surprising that there may appear to be a complete lack of motivation to seek and accept help in the interests of a handicapped child.

3.3 LOGISTICS: INADEQUATE INFRA-STRUCTURE OF DEVELOPING SOCIETIES

Where blindness occurs (and often occurs abundantly) in remote and underdeveloped areas, even the mere identification of children and families in need of help may be a formidable task. Moreover, parents and other relatives do not come forward spontaneously for assistance, partly because their affliction is taken as a matter of course and partly because they are not aware of the existence of a way of life in which handicapped children enjoy special concern and care. Besides this, scattered peasant villages are usually off the beaten tracks and out of reach of transport facilities. These communities may be intermittently served by itinerant missionaries and government officials or may have small regional schools and only modest health clinics (if any) in the neighborhood. Tribute must be paid to the splendid work by such people (usually not trained for the purpose) that has been done and is being done in isolated areas of the world, but the obvious limitations and the consequent effects of children who are losing their vision or are languishing through neglect and inadequate sensory and general experiential stimulation during infancy and early childhood are more than evident to researchers and other professional observers.

On the other hand, the trained professional who arrives on the scene from a westernized background would be amiss to presume that the widely accepted techniques of intervention and the proven and often standardized methods of helping blind children and their families represent the only manner of achieving the goals that should be striven for. The instinct for survival should never be underrated, and we yet have to find out how blind children in tribal communities learn to function in relation to the demands of their own environment. It is known that African children in certain traditional settings have been reported to show little or no evidence of common blindisms; that a keen sense of orientation is sometimes developed by the blind in distant village communities where there is no geometrical outlay of housing and where the unpaved pathways to and from the fields and water sources meander according to the surrounding vegetation and the topography of the landscape. Also, there are blind children and adults in these

communities who join their siblings and companions in tilling the fields, gathering or carrying wood and performing other daily chores. The proposed program of intervention must take the relevant social and environmental factors into account.

An important aspect of logistics is the indispensability of effective follow-up services. The social worker or counsellor is often discouraged when his efforts to motivate parents seem to remain unrewarded and the available services are apparently not sought after. Arrangements must be made for regular follow-up and control, and for continued encouragement of the family. Special interest should always be shown in the child itself, its assets, its potential. Parental pride can be invoked and praise for co-operation should not be spared.

3.4 NUTRITION MOTHER AND CHILD

During infancy, most babies in developing communities are breast-fed, ensuring a certain degree of health and growth by nature's way. However, malnutrition of the mother and later of the weaned infant, constitutes a major threat to the general health of both. Part of the poverty syndrome in rural communities is inadequate nutrition, not only in quantity (e.g. when crops fail or famine sets in), but also in quality. Lack of elementary knowledge in respect of diet is likely to aggravate the ill effects of food shortage. It is common knowledge that a regular Vitamin A deficiency causes xerophthalmia, to quote only one example. It may be virtually impossible for a family struggling for survival to enjoy anything approximating a balanced diet. Fortunately health services, including the provision of general and maternity clinics in strategic locations, are a prominent feature of new dispensations in many developing communities, and the parent counsellor must obviously establish the best possible liaison between the clients and the available facilities.

3.5 RECRUITMENT AND TRAINING OF COUNSELLING PERSONNEL INTRA-CULTURAL

Intervention programs must be carried out by competent personnel. Bearing in mind the numerous considerations discussed above all "foreign aid" (also in the sense of aid offered by persons of one socio-economic culture or another) should be based on the assumption that meaningful communication and mutual trust are best achieved when the client and the counsellor are conversing in their common mother tongue and are able to share confidence in terms of a social and cultural background that is appreciated by both. The counsellor, as a trained and well educated person, may occupy a higher rung on the ladder of personal advancement, but is able to understand the situation of the client in all its implications.

For this reason, the recruitment and training of indigenous staff should be given top priority. "Foreign" organizations are needed to provide funding and expertise, but their knowledge and skills must be imparted to men and women of the local community and an adequate administrative structure needs to be developed in order that both the organization and the delivery of services may be set on a course that will lead to true independence in the developing society.

4. REMEDIAL INTERVENTION IN DEVELOPING SOCIETIES

4.1 COMMUNITY EDUCATION OR ENLIGHTENMENT

The developing society (as also many sectors of industrialized communities) usually lacks the elementary knowledge that help of various kinds is desirable, necessary and available. Information can be disseminated through the school (children are often the best messengers), through clinics and itinerant personnel, and through the media. Even where reading matter does not yet play a vital role, radio and television are now beginning to reach people who were formerly almost beyond public communication. But it is a long process and information is not enough. It may take generations to change attitudes, as experience still proves

in more sophisticated environments, and the social traditions and taboos discussed earlier in this paper may long continue to inhibit positive response on a comprehensive scale. Yet there are societies who have experience in this respect have been encouraging, and the promotion of public awareness should be planned and carried out with the close involvement of members of the group concerned.

4.2 VOLUNTARY AGENCIES AND COMMUNITY INVOLVEMENT

Voluntary agencies including church and missionary bodies, welfare organization and international aid groups, have long made a considerable contribution in providing social, medical and educational services to developing communities. One of the chief aims of such groups should be the promotion of community involvement. Leadership should be enlisted from the indigenous community and cells of "care groups" of parents, professional and voluntary workers formed to interact and to provide supportive services which include the counselling of parents of preschool handicapped children. Once the community begins to run its own welfare ventures, the needs of parents and their handicapped children will become an ingredient of the overall program.

4.3 GOVERNMENT AGENCIES AND STRUCTURES

In newly independent developing countries, government priorities are often of necessity concerned with bread-and-butter issues, and such matters as the education and care of handicapped children usually have to await a later turn. Nonetheless, voluntary agencies and foreign aid groups can bring pressure to bear to provide the most essential medical and educational facilities, even on modest lines to begin with, and to develop parent counselling from these bases. Developing communities and governments sometimes tend to think and plan too ambitiously and then abandon a worthwhile venture for lack of funds. It is wiser and it is more politic to make a small beginning and then to allow for gradual growth as and when circumstances permit. Between doctors' paramedical staff, teachers and social workers, a helpful system of parent counselling can be developed. Further specialization may be introduced in due course when the service has justified its existence and progress has been made with personnel training.

4.4 INTERNATIONAL AID

The post-war period has seen an upsurge of international activity to help developing nations in establishing the numerous structures that are essential for education and cultural pursuits, medical and scientific development, economic growth and recreation. This should be continued, but care should be taken that appropriate planning keeps abreast of spending. Advanced accommodation and equipment are of little use if suitable measures are not taken to train staff, particularly indigenous staff, who can form a nucleus around which a more comprehensive service can develop. There is much to be said for training of home ground as opposed to sending selected candidates abroad. Panels of experts are taken from industrialized to other countries to run training courses and to guide trainees in applying their newly acquired skills to the work situation. This type of training is less costly to the sponsors and usually more productive of the much needed staff in reasonable numbers.

5. SUMMING UP

The incidence of visual handicap amongst children of preschool age the world over has never been precisely established. The available evidence suggests that the numbers are diminishing in Western countries but increasing in many developing societies. These children are not all destined to receive suitable schooling. Those that will be attending schools (and those that will not) would

benefit from early intervention, from health care and from the kind of stimulation and exposure that promotes development. This could in a small way be the preface to a brighter and more rewarding future for thousands of children. It is up to the privileged nations to share their material and human resources with others, and it is up to the developing countries to use these resources economically and judiciously, in order that optimum benefits may be gained by those for whom the help is intended.

SOURCE MATERIAL

There seems to be very little, if any, literature on this topic as it is worded, but much of what has been written generally on parent counselling and preschool intervention is relevant and helpful. The author wishes to acknowledge the stimulation offered by speakers of the platform and from the floor at the International Conference on the Disabled held in Johannesburg, November, 1981, on related subjects. (Report to be published).

LANGUAGE: A KEY TO LEARNING

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(Aruba)

For all children, the use of language is the most important means of learning. For the visually impaired child, the importance of language is indispensable. All our Aruban visually impaired-born children seem to be behind in their language development and are consequently behind in other developmental areas. This conclusion is not based on data from scientific research in this area, it is derived mostly of the practical experience of the day to day work with children.

The importance of finding solutions for the language problem is necessary in order to work on other developmental areas, and to form a more solid basis in their own language.

On the other hand these children will be or are being mainstreamed in primary school where the teaching language is Dutch. This is a big problem, for their mother tongue is Papiamentu.

Papiamentu, what is it?

Papiamentu is a language, found only in the three Leeward Islands, Curaçao, Bonaire and Aruba. It's significance literally means "talking". What makes Papiamentu a language is:

1. it has its own structure,
2. it has gone through a historical process through which it has become the mother-tongue of the majority of the Leeward Islanders,
3. it has its own grammar,
4. it has its own vocabulary.

One cannot trace its structure back to neither English, Dutch or Spanish, as was commonly believed. Thus excluding the possibility that it was derived from any of these languages. On the contrary it has a structure very similar to that of creole languages, but with an Iberian vocabulary.

In 1499 Curaçao was discovered by a Spaniard Alonso de Ojeda. Aruba and Bonaire some time right after that. At that time there were only Indians living on these islands, who descended from the Arawak tribe. The Spaniards soon deported all the Indians to the Dominican Republic, and Cuba as they found these islands barren of rich mineral deposits and therefore considered them "useless islands."

In 1635 the Dutch captured Curaçao, and formed the Dutch West India Co. They were interested in Curaçao especially for its strategic location-right off the coast of South America-mainly for the African slave trade which was very profitable at that time.

The Dutch West India Co. established their economy through the slave trade. At first they tried to recapture the Indians in South America to do the manual labor, but these people resisted and would rather die than be used as slaves. Thus the Dutch then turned to the African slave market. "The slaves brought to Curaçao had little in common but their race, as they were brought from different customs, religions and languages. Taking into account that there were different highly developed kingdoms in Africa, it could be possible that when the Portuguese began with the slave trade, there could have already existed an African Pidgin, or lingua franca, used by the Portuguese to get in contact with the Africans." (1)

The Spanish Inquisition in the latter part of the 16th century brought on another important turning point in the history of the islands. Because of the Spanish Inquisition many Sephardic Jews fled from Portugal and Brazil, especially to Dutch territories. The Dutch West India Co. encouraged these Jewish people, who spoke Portuguese and Spanish, to come and utilize their knowledge in the slave trade. Thus many Jewish merchants settled in Curaçao. They mingled with the slaves to a greater extent than did the Dutch, as they used the slaves to work for them in and around their homes, and the Dutch had them exclusively to work on the plantations. It is through this interaction between the 3 groups - the Dutch, the Sephardic Jews and the slaves - that in the 1700's Papiamentu was born. Through the close relationship between the Jewish people and the slaves Papiamentu has a Portuguese sound.

The first document known was written in 1776 by a Jewish merchant. It is a letter that he wrote to his wife in Papiamentu. As the years passed the structure stayed the same, but the vocabulary enlarged mainly with words in Spanish, English and Dutch. The Spanish came through the influence of the Roman Catholic Church, which fought the Dutch on their beliefs about educating the negroes. They found that it was not necessary, but through the insistence of the church the Dutch allowed some Spanish priests to be brought in.

In the early part of the 1800's a Dutch educational system was introduced, but only for the elite. Towards the latter part of the 1800's the economic situation on the islands became bad that the majority of the working class people had to leave, mainly to Cuba, in order to find jobs to be able to support their families. "As a result of the arrival of the Shell in Curaçao and the Lago refinery in Aruba in 1919, many of these people returned to their islands, bringing with them a "revised version of Papiamentu." (2)

With the establishment of Lago, many people from the neighbouring islands settled in Aruba as there was suddenly an abundance of work at the oil refinery. Through this period one notes a definite growth in the vocabulary of Papiamentu in especially the technical and mechanical terms.

Aruba's location, a stepping stone to South America, in the middle of the 20th century saw a tremendous growth in the tourist industry. This has necessitated the Aruban to be able to master at least 2 more foreign languages, namely English and Spanish. Especially the use of Spanish has had an enormous influence on the island through television, the tourist trade and also quite some immigration to the islands from the Dominican Republic and Colombia.

Today Dutch is still the official language, but in day-to-day life of the Antillian people one will find a very minimal use of it.

"Papiamentu is so firmly entrenched that the Dutch government, in 1956, agreed to raise the Papiamentu to the status of a second official language." (3)

Even though Papiamentu is considered a second official language, it is notable that even in the highly official circles the Papiamentu language is used as a means of communication, except in the courts of law, in the island council meetings, in official government notices to the public, etc. Looking at our mass communication one sees that at least 80% of the available daily newspapers and radio broadcasts are in Papiamentu.

Although Papiamentu is the mother tongue of most Arubans and most Leeward Islanders, the official language in school is still Dutch. Chumaceiro, who lived a century ago, was the first one to make remarks about the disastrous influence of Dutch on the education in Curaçao. The situation has barely changed. In 1978, the government of the Netherland Antilles has installed a committee "Commissie Beleidsnota" which had to study the whole present school system in the Netherland Antilles, in order to present a proposal for a new and better school system, adapted to our cultural and social situation. In December 1981 they presented their proposal: A new school system called the G.A.V.O. (Grondlegger Algemeen Voorbereidend Onderwijs) for children from 4 to 15 years.

They recommend introducing Papiamentu as the instruction language in this whole school system.

Due to especially political reasons, Papiamentu has not yet been introduced into the educational system. This confusing situation for the Aruban children and teachers is reflected yearly in the constant decline of school results. I have to state that there are also other factors that contribute to these poor results as our inadequate school system, class teaching, etc.

Now we would like to discuss the effects of this situation on the mainstreaming of the visually impaired children. Up to this date we have mainstreamed 5 children into the normal education. Of these 5 children we will discuss only the 3 that are now being confronted with this second language problem. The other 2 are still in kindergarden where Papiamentu is spoken.

Although a six year old child with an average language development seems to have a completely developed language, it still has a lot to learn. As Ramon Todd-Dandere says: "At the moment that a child enters school, his linguistic development does not stop. On the contrary, at school a child learns to use its language in a new way: it learns how to write it and how to read it. This gives it a new dimension in its way to communication: the linguistic development also becomes visual, before it was oral-auditive. The relation that the visualisation of his language has with his intellectual development is that the child can use its language the way it uses concrete objects." (4) For the visually impaired child the visualisation of its language is mostly impossible. Instead of visualisation we have to resort to tactile methods, combined if possible with visualisation.

In order to understand the linguistic development in a visually impaired child, it is necessary to understand something about the linguistic development in general. The linguistic development in a person consists of the following elements and goes according to the following structure: reality - conceptual configuration - semantic configuration - syntactic configuration - fonological configuration - phonetic form. Because of the limited amount of research in the field of linguistic development with the visually impaired children and the available information on this topic, it is difficult to compare the linguistic development of our visually impaired children with visually impaired children elsewhere. We also cannot compare the language development - or lack of language development - of these three children with that of sighted Aruban children. This is due to the fact that there isn't any complete recorded language assessment material in Papiamentu we know of and to the fact that our work with children up to now hasn't been completely developed yet as a result of lack of expertise, experience and shortage of staff members.

Although there isn't any complete recorded language assessment material in Papiamentu, some persons have done research in some language areas. In the recent past a vocabulary research among children of kindergarden age was done. Before we discuss the linguistic development of these three children we have to admit that we do not have any structured assessment for reasons mentioned above.

The children in our program

The first partially sighted child who came into our mainstreaming program in 1979 was a 7 year old boy. He had just finished kindergarden, but was so far not yet enrolled into a primary school. Being the only child and having a handicap caused him to be spoiled, and as a result of this he was a little tyrant. In their home Papiamentu was spoken, but his language development was very poor, his vocabulary very limited, his sentences short and his pronunciation indistinct. He had the tendency - a tendency we all have in Papiamentu - to shorten words. He did this out of bad habit, not because he could not pronounce them well. He was not able to converse because he was not trained

to listen. As soon as an adult started to talk to him he started his own conversation and would only talk on a few selected subjects, which he would keep repeating over and over, time after time. He could only express himself understandably when he wanted his wishes to be known and this was only at home or with his younger schoolmates, and sometimes in the classroom where he would walk around and yell.

On analyzing the language situation at home, we have to state that the parents spoke Papiamento well. The mother, a very well meaning lady, was so concerned about the handicap of her son that she did not give him the chance to learn. She did everything for him, even talked for him. She was so high-strung that she did not give our workers any chance to talk to her. During a visit she would talk incessantly, while throwing corrective advices to her son during conversation. In order to be able to work with the boy we had to first concentrate on helping the mother change her behaviour. When he started primary school he was not prepared to enter the school situation he was about to get into. And he was not at all prepared to be taught in a foreign language: Dutch.

Research has shown that the sighted Aruban children have a lot of problems mastering the Dutch language. It is only a minority of all school children that finishes primary school without repeating a class once.

Introducing a foreign language to this boy had a very negative impact on him. On entering our program he could count to 10 in Papiamento, he could name numbers, but when he was taught to count in Dutch, it confused him so much that for more than a year he could not even count in Papiamento any more. Fortunately it was possible to help him in the language development of his mother tongue. He can converse now, his pronunciation is clearer, his sentences are more complex, his vocabulary is larger and his comprehension of the language has increased. But in comparison with his sighted schoolmates, he is still behind.

To keep him mainstreamed he had to learn to speak, write and read Dutch. To initiate that we were obliged to take him out of school for one year and give him lessons on an individual basis. At the moment he is mainstreamed again and gets constant private reading and language tutoring in Dutch from the resource room teacher. He is functioning at 2nd grade level. His syntactic development in Dutch is still much below the level of a 3rd grader. In order for him to be able to function at a primary school he will have to have constant tutoring. This is due to his slow comprehension of Dutch and his inability to concentrate as he should at his age.

The other child was a Papiamento speaking girl who came into our program 2 years ago, at the age of 9. She had become severely partially sighted the year before due to a brain tumour, at which time she was in 3rd grade. She was a bright little girl and was very eager to learn. On entering our program, she received individual lessons for one year in order to prepare her to reenter primary school. She quickly learned to use her remaining vision, was talkative and spoke Papiamento well and Dutch fairly well. Her advantage was that prior to becoming visually impaired, she had mastered Papiamento and Dutch at the level which could be expected of a child of her age. Because of illness she started having problems in reading and spelling about a year ago, but through the intervention of the resource room teacher this situation could quickly be remedied.

The last child we will discuss is a visually impaired little girl, age 7. When she came into our program, she was already in 1st grade. Her language development in Papiamento was terrible; this was due to her home environment. Her parents as well as her social surroundings have a very poor pronunciation and limited vocabulary. Thanks to the help of professionals and the input on the parents side, she made great progress in her pronunciation. This will enable us to assess her vocabulary. Because of her minimum participation in the classroom and due to the lack of comprehension of Papiamento, we realized that she

is definitely not primary school material. With the lack of a basis in her mother tongue, she will never be able to learn in a 2nd language. So far the extent of her knowledge of Dutch is her ability to count from 1 to 5. Therefore it has been proposed to the parents that it would be best for her to have a psychological test done in view of her going to a school for special education, where the lessons are given in Papiamentu. If we compare these 3 children we come to the conclusion that the language development in the two children born with a visual impairment is very much the same. Both children have shown and still show a large deficiency in their mother tongue, especially when it comes to the syntactic development. The child who became visually impaired at a later age was not behind in her syntactic development, neither in Papiamentu, nor in Dutch. This brings us to the question: How long should it take or does it take until a visually impaired child moves towards the same syntactical level of complexity.

The research done on a relatively small group of blind children by Selma Fraiberg (5) indicates that blind children have an average semantic development as that of sighted children. But that there is however a quantitative difference due to the lack of exteroceptive experiences in blind children. To develop language the blind child is completely dependant on the people in his surroundings. Selma Fraiberg also states that blind children show a syntactic disadvantage in comparison with sighted children of the same age. This syntactic disadvantage can possibly be caused by experiential poverty which accounts for the blind child's ability to combine two concepts. Her research is the closest material we could find to compare our partially sighted children with. We may conclude that most likely severe partially sighted children are in many ways also dependent on the people in their surroundings.

The most important conclusion in this paper is that visually impaired children in Aruba enter primary school with an extreme retardation of their own mother tongue. However, they have a still greater barrier - namely the Dutch language - to surpass. And this causes a second handicap. Will mainstreaming visually impaired children in this educational system ever be successful?

Do our Aruban visually impaired children have a fair chance in this school system, even if they are normal intelligent? Do they? Isn't it about time Papiamentu is introduced as teaching language in our schools?

The title of this paper is "Language: a key to learning." However if one uses a foreign language in primary school, we must ask ourselves are not we tongue tying these visual impairment children. Is language then still the key to learning?

Footnotes

¹ A Short survey of the social history of Papiamentu. Ramon Todd Dandere, M.A. Third Biennial Conference of the Society of Caribbean Linguistics - Aruba, Sept. 16-21.

² Idem.

³ A grammar of Papiamentu. Peter Fodal Kamon. Publishers in print.

⁴ Introdukshon di lenga materno den enseñans un mester? Ramon Todd Dandere, M.A.

⁵ Insights from the blind. Selma Fraiberg.

CHARACTERISTICS OF YOUNG BLIND CHILDREN

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For some time now, those in the field of education for the visually handicapped have debated the question of whether the delays in development of young blind children are the result of deprivation of experiences or whether the delays are inherent and because the children follow different norms of development. The results of Fraiberg's study with her ten blind children has been so widely distributed, probably because there is so little information regarding the development of visually impaired children that is otherwise available, that most people who are even tangentially affiliated with the field of intervention with visually handicapped children are aware of the results and of the belief that the children mature at a slower rate than do their seeing peers. And yet we continue to see children that perform at a much more accelerated rate than did those in Fraiberg's study. Is this a normal variance among the blind children or is it a reflection that the children are capable of doing more than they have been perceived as capable of doing?

To answer this question, there has been an attempt to more carefully document the characteristics of the visually handicapped preschool population. This paper is addressed to that topic.

The population studied has come from several sources: The FIFTY Project (Visually Handicapped First Two Years), a project funded by the Western Pennsylvania School for Blind Children to serve children from birth to age two; the standardization population for the Adaptive Performance Instrument, a project funded by the United States Bureau of Education for the Handicapped; data collected by those who have used the developmental Hart's Charts, an effort that I have been engaged in during the past 16 years; children that I have observed on a consultant, inservice or advisory capacity; my research with multihandicapped children; and the work of several doctoral students. Thus, the population is not limited to one geographical area or to one intervention program.

To relate all definitive characteristics in the short time that is available today would be unrealistic, not only because of the large number of variables that are involved, but also because most of the research is being continued and so many of the data are tentative. However, there are some characteristics that seem to be emerging from among the many factors that are being investigated.

The population of visually handicapped preschoolers is a very diverse one. Some children are blind because of hereditary factors, from viral or bacterial infections, from maternal chemical imbalances, from drug abuse, or from incidents occurring around the perinatal period such as a lack of oxygen, too much oxygen, intraventricular bleeds, etc. These incidents may also cause accompanying handicapping conditions. Thus, although blindness has the least incidence of all handicapping conditions in the United States, the variance between those affected is as great or greater than for all of the other handicapping conditions. To study the characteristics of blind children, then, is a very difficult process; the numbers are so small that one is never sure of having a true picture of the total population, and the scattered population of young children makes it difficult to obtain groups for study. In addition, the differential effects of early intervention have become intervening variables in our efforts to document the characteristics of the handicap.

However, one etiological factor seems to be emerging. If the visually impaired children have sustained a grade 3 or 4 intraventricular hemorrhage, their progress is not as rapid as children with most other etiologies. There is

less variance among the children who have suffered such damage, and they are found to have multiple problems, most any one of which would prevent normal development. With the life sustaining measures that are now available to children born between twenty-five and twenty-seven weeks of gestational age, we are now seeing more of these children. This fact is something we need to consider as we plan our intervention programs.

A behavioral characteristics of the children that we have studied that has been noted previously in the literature is resistance to the prone position. Most of the babies and young visually impaired children that have been involved in our studies have also resisted the prone position, particularly if they have been intubated as newborns. The longer the children have been allowed to lie on their backs, the more resistance they seem to have to the prone position. However, once the children become comfortable with its necessity, they seem to learn to enjoy being placed on their stomachs.

Development of the prone position seems to be particularly pertinent for the development of one of the other characteristics that has been frequently noted among young blind children - their failure to reach at the average age of development. The failure of the children to assume the prone position as very young children seems to have impact on their failure to achieve early reaching. Ammon and Etzel (1977) recognize that both shoulder and shoulder/arm stability are necessary to develop reaching skills and present a model for understanding the multiplicity of systems that contribute to the skills of reaching, prehension and related hand skills. Pearson and Williams (1972) discuss the prone position as a facilitator for developing the symmetrical reflex and subsequently extension which is necessary as a prerequisite to reaching. Bobath (1971) notes that abduction-flexion of both upper and lower limbs is among the "most important stages of motor development" (p.6). Bobath believes that the children in prone can develop the prerequisites for reaching while in the prone position by transferring their weight to one arm and then rotating the shoulders and spine. Finnie (1975) also has discussed the reaching behavior by noting that when the arms are used for support in a prone position, the children are soon able to place the weight on one arm and reach out for a toy with the other.

Molnar (1974) worked with young retarded children who had no evidence of neuromuscular disability and found that they were able to pass target behaviors within a month after they had been taught prerequisite postural adjustment skills. The children we have studied who have vision problems with no other accompanying conditions have become comfortable in prone within the same month's period of time. Increased head balance has also occurred, and, if they are introduced to the position early and are given sufficient time in the prone position, they learn to reach out within the normal range of development. Thus, beginning intervention early and placing the children in the prone position for periods of time each day seems to facilitate reaching within the normal time variance of children with vision.

This very early intervention also seems to help with a problem that has plagued those who work with older blind children -- keeping the head up. To wait until the children begin mobility training or until they enter formal educational programs is far too late; the data seem to suggest that those children who attain good head balance with a head erect position before they are encouraged to sit independently are those who maintain their heads up for later sitting balance. Those who learn to sit with a head down position persist in this position and carry it over into standing and walking postures.

While the lack of vision fails to give head righting cues, the children can be taught kinesthetically to keep their heads up. Those who have any useful vision at all can be reinforced for the upright position by using whatever visual stimulus that seems to be rewarding for them.

Hamilton, the physical therapist with the previously mentioned VIFTY Project, has noted that there is a resistance to prone in the totally blind, instability at the shoulder girdle, delays in assuming transitional positions, delays in weight shifting in the prone position, decreased axial rotation, lower muscle tone and less movement. All of these can be attributed to less early experience in the prone position. If the prone position is assumed at a very young age, the children tend to develop better movement patterns at earlier ages. Allowing the children to be in the prone position and encouraging early movement also helps develop more normal muscle tone. Protective reactions are easier to develop in children who are active and encouraged to move about than in children who are placed in relatively stable positions and securely protected against falls.

Another observation made of the children is that creeping is a factor that seems to affect later walking skills. Most blind children do not creep unless taught specifically to do so. Creeping seems to have an effect upon later walking, however. Although children have long been able to walk without first creeping, those who have learned to walk without first creeping or undertaking activities that foster the same balance, rotation and weight shifting that creeping develops, are more apt to have the broad-based gait and the "duck-waddle" so often associated with blind children. Creeping not only encourages weight bearing, rotation, and balance, it encourages the children to support their heads and to develop the musculature patterns for good head support. Reciprocal creeping has been noted as a good precursor to more normal gaits.

Another factor noticed in our work with the young children is that the young black infants who are blind but have no additional handicapping conditions appear to follow the motor developments of black children in general. Espenschied and Eckert (1980) report that the African newborn is ahead of the European newborn in skeletal maturity and motor development. We have noted two singularly handicapped blind children who were not only at age level in their early attainment of motor skills, but were ahead of their seeing Caucasian peers.

Other characteristics also appear in our work with young visually impaired children. As noted by many authors in working with older children, any amount of vision seems to affect the motor skills of the children. For example, the totally blind children not only resist the prone position, they are more inclined to use their head as a point of contact with the floor.

Although those with any amount of vision seem to reach their developmental milestones more quickly than those who are totally blind, the children seem to have great variance in this matter. Also, some of the blind children who have developed more quickly have later turned out to have some degree of vision.

Any amount of vision seems to benefit the children, whether singularly or multiply handicapped. There are fewer motor delays, greater tolerance of the prone position, greater head righting, more motor movement and more normal ages in reaching and motor functioning. The children are also easier to intervene with because the vision can be stimulated to encourage the head righting, prone position, reaching and other movement. Perhaps it is not the amount of vision that is necessary but the type of reinforcement used that is the important factor, for Ferrell (1980) found that the Sonic Guide could be used to develop these same skills in her youngest blind subject.

The prone position has been noted as a good facilitator for reaching toward an object. The prone position where the children are encouraged to extend their arms and maintain their weight is also a good way to develop other fine motor skills. Children who have been supported in their efforts to reach out for different objects and to shift their weight in doing so can more quickly cross the midline and bring their hands together. These activities, as well as the encouragement of creeping on various textures, seems to reduce the amount of tactile

defensiveness that some children appear to have. This defensiveness frequently seems to be associated with light touches. By using firm touches when working with the children and introducing many different textures early in a natural environment, much of the defensiveness seems to be averted. The prone position seems to aid in this, as does creeping and encountering various textures as the children move in their environments.

When working with very young children, it is difficult to determine the exact amount of visual acuity they have. One ophthalmologist voiced it very well when he stated that we must wait until the children are old enough to tell us what they see before we can determine their acuity. However, the visual preference testing espoused by Fantz and Nevis (1967) and Fagan (1971) has been used very successfully by Ferrell (1982) in determining the visually acuity of the infants in her study. Although the technique could not be used universally with all of the children because of other variables, the technique was useful to determine more specifically the amount of vision than were traditional ophthalmological examinations.

One of the dangers when working with young blind children is in assuming that they are, indeed, blind. Many of our babies, when first worked with, reacted as totally blind. After stimulating them over a period of time many have learned to use what remaining vision they have and a few have turned out to have very useful vision. Thus, it should not be assumed that there is no vision. Early techniques should include a careful visual acuity assessment, appraisal of the use of vision, and visual stimulation even though initial responses may be negative as part of the intervention.

Another factor that should be mentioned when relating our findings when working with young visually handicapped children, is that of acceptance. Much of the literature in parenting is spent in discussing the importance of acceptance of the children and their handicaps. When working with them, however, it can be determined that several of the parents never have accepted the fact that the children are blind and yet they are still able to provide a nurturing environment. Because it is such an important aspect and so opposite to what we have believed for many years, further investigation needs to be made into the subject. Parents who are still fighting the acceptance of a problem are able to provide materials and interact with their children if given a model of interaction and then allowed to demonstrate that they understand the model that has been presented to them. In fact, this interaction with their children seems to help many parents hasten their acceptance of their children - they discover that their children are able to learn and that they can be effective parents to them.

Parental prolonged and deep depression seems to be more of a problem when determining which parents will learn to successfully interact with their children than does acceptance. Many parents who have had a history of depression add the problems of having a blind child to pre-existing difficulties and seem overwhelmed. In every case that we have examined, however, this deep depression had causes in addition to that of their children's blindness. In fact, most had a long history of depression. Although our other parents have reported short periods of depression, once they have learned to relate to their children, this became lessened in intensity. This has not been true of the parents with prior depression.

This appears to have great importance in determining the types of intervention that we must deliver to the children and to their parents. More needs to be done to show the parents specific information as to the types of intervention that they can carry out with their children. We can tell the mothers to place their babies on their stomachs or we can demonstrate how to do it, using a small towel under the babies' arms to flex their bodies if that is indicated, and then demonstrate how sound toys, lights, and kisses can be used to help the children

lift their heads. Having the parents demonstrate that they can do the same and taking pictures with a self-developing camera can aid the parents in seeing the desirable position for them to practice. Such activities can act as a diary for determining when the children develop various milestones as well as be used as a record for the parents to verify a steady rate of progress and that much has been learned. All too often the parents become overwhelmed by what their children can't do and forget all of the things they can.

Not only does demonstration help the parents determine specifically how to do an activity, it also aids in their acceptance of their children to have someone else interact with the babies. Parents have related that "They told me I should get my child on solid foods. I tried and she didn't like them. No one told me what to do next until you showed me," and "I thought that no one even wanted to look at my baby until you came in and asked to hold her. When you told me she had pretty hands I nearly died. I hadn't even noticed. I'd been too busy looking at her eyes. I'll never be able to thank you enough for helping me to really look at her." In both of these instances, acceptance of the children occurred because the mothers found that they were capable mothers and that the babies were babies first and that they just happened to have difficulty seeing.

One of the interesting things noted when working with the mothers is their interpretation of their children's temperament. When the parental and teacher's ratings are compared, there is often a discrepancy. Even between parents there are often differences. This seems to be related to the way in which they deal with their children. One mother will see a very demanding multi-handicapped child as easy, while another will see an easy-going blind child as very difficult. The temperament area needs further study and is one that we hope to analyze further to determine correlations with other factors we are studying.

These, then, are a few of the characteristics of the population that we have been studying. In answer to the question of whether the children are slower in their development because of an experiential deprivation or whether they have different innate rates of development has not been determined. One thing has been found, however. A more normal rate of development can be obtained, particularly in the motor area. How much this development can be assisted is still unanswered.

The American Foundation for the Blind recently called together a small committee for suggestions in this regard. That committee recommended that norms be gathered on a sample population to determine the feasibility for a larger more intensive study of the characteristics of the blind population. One thing is certain. Control for intervention factors must be made. We will still have the environmental-deprivation/innately-different question unanswered unless careful data are kept regarding the type of intervention that is carried out with the children. A counseling model, counseling with some suggestions to the parents, a direct instruction model, and a parent-as-the-child's-first-teacher model all are in use. Accountability for our intervention strategies also needs to be considered when we look at the characteristics of the children. "The Making of a Blind Man" may begin in the cradle.

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"BABY DANCE"

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(U.S.A.)

I first learned of "Baby Dance" through a small article in our local newspaper and then saw a brief presentation on the television news. Immediately I knew it was just right for my then six month old visually impaired daughter, Kate. The children and mothers, sitting in a circle on a large exercise mat, were moving through rhythmic movement patterns experiencing recently acquired skills and being taught new patterns. The over-all feeling in watching the children and their mothers was that moving is fun!

It had already become apparent to me that Kate was not moving as other children her age did - nor did she seem to have the strength to start sitting up or crawl. She could not push her chest up off the floor by extending her arms. She hated to be on her stomach and would bellow if left there for any amount of time.

At the time I called the Creative Movement Center in Needham, Massachusetts, where Baby Dance originated, I was afraid to even mention Kate's visual impairment, because I was afraid that the teachers might reject us. I felt, however, that I had to be honest with her teachers in order for them to consider if they were ready to accept a special needs child. In fact, a number of children with varying disabilities had already enjoyed Baby Dance and Kate's teachers welcomed us into the class. This was Kate's first "mainstreaming" experience and my first experience advocating for Kate outside the medical arena.

Kate had been born with retinoblastoma, a form of eye cancer. She was very fortunate to have had her life saved by means of radiation, but her eyes were deteriorating and both retinas were detached. During our first Baby Dance series, a ten week semester, Kate lost both her eyes. I mention this as Baby Dance played a crucial role in how we coped with her surgeries and loss of hope of sight.

Why is Moving so Important?

Norma Canner, a teacher of dance therapy in Cambridge, Massachusetts and author of an inspiring book "...and a Time to Dance" tells us "that for the young child movement is a way of exploring and discovering his world and himself. As an infant he moves indiscriminately. He soon discovers and then learns to control his body. At points in his development he discovers his arms, legs, his eyes and ears, and soon realizes these are part of him. His self image is formed in part by these discoveries of and about his moving body. His body is his basic tool for dealing with his world, before he learns to verbalize and intellectualize his thoughts and feelings."

What is Baby Dance?

Baby Dance is a set pattern of simple, primarily passive exercises done to music which may be sung, played on a simple instrument or recorded. It is a set pattern which the child comes to anticipate and enjoy. Ideally, the mother may learn the pattern in a group setting where there is an opportunity for sharing and support. Baby Dance can be done, however, by a single parent or teacher, anywhere.

The pattern of the exercises is totally arbitrary. This is not a method course. The interested parent or teacher considers the kinds of skills a

child is learning and those skills he wants the child to begin to focus upon and then the parent or teacher "choreographs" a short dance that utilizes the desired movements, broken down into the simplest steps possible. The different kinds of movement in any one dance should probably not number more than a dozen, as if there are too many movements neither the mother nor child will be able to learn the desired sequence.

Typically when Kate and I went to Baby Dance, the dance itself would only last about two minutes. This seemed to be about the optimum amount of time, as we did not want the children to become exhausted. In addition, children this young have very short attention spans. After the Baby Dance ended we wanted the children to have energy to move on to other movement activities.

One way to conceptualize a Baby Dance is that it is a warm up session that moves all of the parts of the body. It was often easiest for us to warm up from head to toes, as this gives a kind of direction to the choreography. For instance, we might start out tapping the child's head with its hands, then do a series of arm circles and hugs, and eventually move down to tapping the feet together.

While Baby Dance is primarily passive exercise for the child, it is active exercise for the mother or father. In other words, it is you that is dancing or moving with the baby, not the baby initiating the dance. All children respond to the parent's enthusiasm as the parent places the child through the exercises. This enthusiasm is infectious and often the child giggles as he comes to expect a favorite movement. The parent's body movement is often used to augment the range of activities possible. For instance, a child may sit straddling a parent's foot and be lifted up and down in the air. Another favorite movement which we used toward the end of the dance for a finale was for the child to be swung upside down in a circle while the parent held onto the child's hips.

The parent needs to watch her child's response to each exercise, never forcing the child to move beyond comfortable limits. My daughter is very limber and can easily touch her shoulders with her toes, but other children in her group were not so flexible. The exercise program should be invigorating, but not taxing and certainly not hurtful.

As we watch the slides of the first baby dance my daughter and I learned, please think of the following aims:

- 1) We want to increase the child's awareness of his body and help him begin to build a realistic, positive and confident body image.
- 2) We are beginning to help the child learn to isolate his different parts of the body so that he can learn about the great potential of each part.
- 3) We want to help build strength and endurance.
- 4) We wish to stretch muscles and make them more supple.
- 5) Through lifting and swinging we will stimulate the vestibular system which helps us with balance and movement detection and tells us where we are in space.
- 6) For the visually impaired child we also particularly want to supplement the sensory information through stimulating other channels. We want to talk to the child as we are helping him learn the exercises. We want him to listen to the music. We want him to feel the mat and other equipment. We want him to feel our muscles working.

7) We want our children to learn to move aggressively using the fullest range of motion possible.

8) We want our children just to be together with other children and be aware of their presence.

The child in the slides you are about to see is Heather. Here she is seven and a half months old. She was born with bilateral coloboma and cleft lip and palate. She has recently joined the Perkins Infant Toddler Program and here her mother is looking on as I show her the Baby Dance. Another mother and her

son David can be seen in some of the slides. When David was about five months old he lost much of his vision subsequent to an accident.

Heather is working on learning how to sit up. We are helping her with this by doing many exercises with her being supported in the sitting position. We are also working on building strength in her upper body. We are showing her that it is fun to sit up.

At our first mainstream Baby Dance class we, as a group of about a dozen mothers, came together with our children aged about three to fifteen months. The teachers taught us about half of the Baby Dance sequence the first week. They demonstrated the sequence using one of the children in the group and then had us return the demonstration. We were all very excited to see that we were able to learn the sequence in spite of being a little nervous. And most of all the children were having fun! During the second week we finished learning the dance and ran through it three or four times slowly to be sure we understood the directions.

Each week of the remaining eight sessions we started our baby exercise program with the Baby Dance. Because we had also practiced the sequence at home several times during the week we no longer needed the teacher to call out the directions after the fifth or sixth week and instead we listened to the music and moved to it. Also by then it seems as if the children had memorized the dance as well, and they appeared to be anticipating what was coming ahead and would take joy in the anticipation.

In addition to the enthusiasm which was generated by the teachers, a great deal of energy also came from the music which they selected. The same song was used each week for the Baby Dance. We used tape recorded music, but children love to hear their parents sing and also enjoy simple instruments. Baby Dance reinforces keen listening skills as the children move to the rhythm of the music and changes in the music. The tone should be up-beat and relatively quick tempoed.

A number of the baby dances that my daughter learned used a simple homemade piece of gym equipment we called a "Rollie". It is a roll about six inches thick made by covering a piece of cardboard tube (a carpet tube) with a piece of foam rubber. We secured the foam rubber to the cardboard using staples and then covered the staples with tape so that the staples could not come out and hurt the children. Then we covered the rollie with a pillow case which we tied on with a piece of ribbon, so that it could be easily removed and washed. Our cardboard tubes were donated by the local carpet merchant.

Every child should have a rollie made for him that he can take home and use during the week to build up strength. As you saw in the slides, children were placed over the rollies and had brightly colored toys or sounding toys placed in front of them to reach out to.

At each session the first ten minutes or so would be used running through the actual dance sequence similar to the one I presented and then for the remaining thirty-five minutes we would move on to use other simple gym equipment. We would split up into small groups and the two teachers would show us how to use the equipment safely.

One of the most popular pieces of equipment was the full size trampoline. All of the children were placed together on the trampoline and then were gently bounced by one of the teachers moving up and down. Children were placed on their stomachs to develop their chest and neck muscles. Each child was bounced while being supported to sit or stand. Often this piece of equipment was used at the end of the session, as it helped the children to relax. Inevitably, all of the noise would cease and the children would lie down and enjoy the ride.

Since most of us do not have a large trampoline available, you might try using a large blanket and place the child in the blanket. While holding on to the edges gently give the child a similar up and down movement experience.

While some of the children were playing on the trampoline, often others would be learning to move along a very low balance beam which was padded with rug scraps. The children would creep along the top of it or stand next to it while holding on for support. In another baby dance class my daughter attended we used a piece of foam rubber covered with fabric in place of the balance beam.

Another simple piece of gym equipment to build is the rings. These were brought down very close to the ground, but high enough for the child to reach up to and swing forward, backward and side to side, while being supported by the parent.

Every program should have a ramp. Ours is covered by carpet scraps. Infants can be rolled side to side down the ramp or be assisted through a somersault. Children who are learning to crawl can have their mothers go to the top of the ramp to provide encouragement for the child to creep to them.

Very inexpensive equipment is also fun for children. For instance, a child can be gently pulled to sit as she holds on to a small hoop. Larger hoops can be made into imaginary tunnels for children to crawl through. Brightly colored rubber balls and balloons are universally loved by children and encourage exploration and movement.

The time for baby exercise at the movement center just seemed to fly by. Each week we looked forward to coming together to see one another and the tremendous changes occurring in the children. While we all were together for the main purpose of learning ways to help our children move and develop, there were always times to talk about how our lives were going. The teachers did not pressure us to move quickly from one activity to the next. There was time for hugs and even a quick diaper change or fast snack if a child was hungry. We were encouraged to move along and take full advantage of the center, but not at the expense of an unhappy child.

Emotional Support

As I mentioned earlier Baby Dance can be learned individually or in a group setting. It was very beneficial to me that we learned in a group. On our first day I was very nervous about how we would be received by the other mothers. I did not announce that Kate was visually impaired, but when the teachers used sounding toys with Kate and as we talked informally between activities, the mothers quickly learned that Kate could not see. They asked genuinely caring questions. They brought their own children over to be near Kate and shared toy ideas that might be especially interesting to Kate.

The other mothers helped me get through the eye surgeries that Kate was undergoing at that time by just accepting Kate who returned to class the week after each surgery. The mothers did not appear startled by Kate's appearance. In fact, they made a point of telling me how cute she looked and they were amazed by her new prostheses when they were inserted.

I remember saying to myself at that time, if these women who have had no experience with blind people can accept Kate immediately after surgery, then maybe Kate is going to find acceptance and caring people throughout her life.

I knew there would be many emotional ups and downs ahead, but it was a great help to me to have the teachers and parents support us through this difficult time in our lives. I will be forever grateful to them.

The Visually Impaired Child

Having discussed some of the basic elements of a baby exercise program, I would like to turn my attention to the visually impaired child. The following story by Jo Weisbrod rings very true to me when I think about my own daughter and her fear of moving out into the world. Jo Weisbrod speaks of a blindfold

walk she once took and a new mode of motion which she saw as necessary for survival in a sightless world. She said, "I felt my hesitancy to move and my willingness to be still until helped to move." Once she began to trust her guide and move out with him, she said, "I felt the tendency to touch objects lightly and twist sideways to use my side rather than my front to meet what was ahead. I found I bent my arms in slightly and took smaller shuffling steps. And finally, I tried to move out aggressively into space and discovered a deep fear which made me stop."³

Jo Weisbrod speaks of this hesitancy of movement as a blocking of momentum. Momentum here refers to the flow of energy and the lack of residual muscular tension throughout all body parts. The flow of energy refers to a full connecting, a fluidity of flexibility of the neural impulses which must take place for full, spatially and rhythmically clear motion. When energy flow is full, momentum is strong, she says. There is a kind of grace and ease to the person, a naturalness.⁴

When momentum is stopped or blocked unusual movements emerge. These are blindisms. There are, of course, other possible explanations for blindisms, but this one makes sense to me. Jo Weisbrod feels that the blocked momentum is usually connected with some kind of fear or terror which has incorporated itself in the body and externalizes itself in motion. It is a kind of paralysis which must be remedied, if a person is to achieve freedom of motion and expression.⁵

Jo Weisbrod especially observed the fact that a new child was first observed as having a sight problem by other children in terms of physical motion (not in terms of lack of or impaired vision). The other children noticed a slower speed and a kind of hesitancy.

Bringing the Baby Dance Program to Perkins School for the Blind Infant Toddler Program

The Infant Toddler Program at Perkins School for the Blind in Watertown, Massachusetts is a very unusual program. It actually does what it professes to do. We, the parents, are encouraged to bring our ideas for the programing and these ideas actually have been accepted and augmented. About a year and a half ago we started to do the same Baby Dance warm-up that Kate first learned in her mainstream class. For the most part the children seem to have enjoyed the experience.

There are some key elements in designing a movement program for very young visually impaired children (or to be kept in mind if a child is to be mainstreamed). The greatest single factor is minimizing chaos and extraneous noise. There should be one group leader who gives the directions. When there are several conversations or directions coming to the visually impaired child, he becomes overwhelmed and confused. Norma Canner suggests that the teacher can reinforce the learning by emphasizing the movements with her voice. For example, she might say, "We go in...we go out." Or "Our hands are high...our hands are low."⁶ The parent or teacher then assists each child gently through the desired movement, but does not add further verbal directions to the child.

It was very valuable to have had the experience one day recently of having a volunteer who works with the children observe our dance. She herself is visually impaired. She noticed as the dance progressed and the excitement peaked the noise level in the room grew to a crescendo and all of the children burst into tears. She herself experienced total confusion as to what was happening and what was being asked of the children. It renewed for us once again the necessity for as little extra noise as possible. It must be remembered that the children not only are very young, but most have very little usable vision and that being asked to move may be scary enough without adding bedlam.

The movement leader, in this case myself, must also earn the trust of

parents and children alike - that everyone will be safe and no one will be hurt. Using a consistent, well defined space can aid children who are visually impaired in enlarging their personal use of space according to Jo Weisbrod.⁷ Once the child recognizes that the space is safe, he can move aggressively and with greater momentum. We exercise on a large carpet which the children have come to know as being relatively safe to move across (barring toys left around by other children).

Another means of promoting the feeling of safety and security for visually impaired children is to focus on making transitions from one activity to the next gradually, smoothly and again with the least chaos possible. I have found that all infants, even sighted ones, cry if they rushed too quickly or abruptly from one activity to the next without being given time to be held or spoken to quietly.

Music is helpful in uniting the group in coordinated activity. Visually impaired children do not have the advantage of being able to watch their mothers and the other children and imitate the movements they are seeing. The auditory channel then gives a means of organizing the activities. Children can be given simple instruments to play to the rhythm of the music used in Baby Dance. Guests may come in and share their instruments and when possible allow the children to touch the instruments.

Visually impaired children especially should be dressed in the minimal amount of clothing possible (maybe just a diaper). If undressing a child in a structured program is just not possible with the time allotted, then at the very least children should have bare feet to reach out to feel the real limits of the floor and to touch others. Bare feet encourages greater freedom and reduces the chance of children hurting themselves or other children, Norma Canner points out.⁸

She also points out that children need unstructured time and freedom to express themselves. Children who have experienced many failures tend to be afraid of involving themselves in situations that do not have a predetermined end. The teacher needs to motivate and stimulate the child to move.⁹

Children who do not want to participate are not forced. I try to make sure a child knows he may join in or just observe from a comfortable distance. Parents especially need to know that they do not have to bow to peer pressure or pressure from me to enter into any segment of the dance and it is they who are the judge of what is best for their children.

A focus I hope to develop more in the future is learning more about how each part of the body moves and all of its potential. The toddlers will be encouraged to shake their heads all around, open their mouths and stick out their tongues and wiggle their noses!

As you can see, many of the children in the Perkins Infant Toddler Program are no longer satisfied with passive exercises. They want to be up and moving on their own. Now we are challenged by trying to grow with them. Our dance program lasts at most ten minutes during the very busy one hour the parents and children share together. We start our dance in a circle and hold hands together. Infants and children who cannot walk are carried facing into the circle. We walk in one direction, then reverse. We come together in a tight circle and then expand to a very large circle. We hop, jump and run and reach up and down ("We feel big all over...we feel tiny.") Then we move to the ramp where children may do a somersault or creep or roll down the ramp if they wish. We are working to reduce the noise level always. Each week the pattern is quite similar so that the children will know what may be coming ahead, but we also vary the movements somewhat to focus on new skills the children are learning at home.

A number of children in our program are multi-handicapped children. They, too, enjoy Baby Dance, and should participate as fully as possible. Here, Mark, a two year old Downs Syndrome child who is also visually impaired, is being assisted by his mother and teacher in sitting up and pretending to row as we all sing, "Row Your Boat."

In closing, the most important ingredient according to Norma Canner, for a successful dance experience is enjoyment. She tells us that we need to provide an atmosphere where people can feel free to express themselves and where children can experience a sense of success and satisfaction.

Dancing with children after all is not a new idea. It has been done through the ages. The setting aside a specific time to dance and the development of goals is what is new. Baby Dance can be done anywhere in the world. It requires only parent enthusiasm and teacher support. Baby Dance begins to fill what appears to me to be a great void in programming for movement for very young children.

Baby Dance has become a very special part of everyday life in our home. Baby Dance after all has to do with forming relationships of all kinds - children with their parents, teachers, and other children. It has helped my daughter and me build a more fun-loving and intimate relationship.

Footnotes

¹Norma Canner. ...and a Time to Dance. (Boston: Plays, Inc., 1975), unpagued.

²See attached addendum.

³Jo Weisbrod. "Body Movement Therapy and the Visually Impaired Person," Dance Therapy. Focus on Dance VII. (Washington: American Alliance for Health, Physical Education and Recreation, 1980, p. 49.

⁴Weisbrod, p. 50.

⁵Weisbrod, p. 50.

⁶Norma Canner.

⁷Weisbrod, p. 51.

⁸Norma Canner.

⁹Norma Canner.

¹⁰Norma Canner.

Blueberry Pie A Dance choreographed at the Creative Movement Center, Needham, Massachusetts . Background music from Blueberry Pie by Bette Middler on the In Harmony album.²

- 8 Bounces (child sitting on your lap facing you. You are sitting on the floor on a mat or blanket.)
 - 16 Lifts (you first cross your right leg over your left at the knee, have the baby straddle your foot, and gently lift him up and down to the music.)
 - 16 Lifts (now you have the child lifted with your left foot.)
 - 4 Rocking Horses (Place child on your shins with both of your legs together. Rock onto your back and as you do your legs will lift the child into the air: Rock on to back and then return to a sit.)
- Place the child on the mat on the back, head away, feet near)
- 16 Bicycles (Move child's feet and legs as if she is on a bicycle.)
 - 4 Cross opposite arm and feet to meet in the center of the body and then stretch . open - first with the left hand to meet the right foot and then the right hand to meet the left foot.)
 - 2 Pretzel Bends (Gently bend the child's feet up to touch the shoulders - or as close as you can bring the feet to the shoulders.)
 - 8 Arm Circles (Move the child's arms up over the head, then out to the sides, and then down against the body and repeat.)
 - 4 Hugs and Open (Bring the child's arms across the midline and hug the child's chest with its arms, then stretch the child's arms wide open.)
 - 4 Sit ups (Holding the child's hands, pull the child up to sit.)

Now to the Rollies for the last measures of the song:

- 8 Slow rolls while lying across the roll on the tummy forward and backwards.
 - 16 Sit astrides (while sitting with the legs straddling the roll, rock from left to right, back and forth.)
- Finale - An Air push up. (Lift the child into the air and push her up high) and then a kiss!

* * * * *

FACILITATING PEER INTERACTIONS OF A MULTIHANDICAPPED BLIND PRESCHOOLER

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PURPOSE:

The purpose of this presentation is to present data on the effects of specific types of teacher verbalizations on the peer interactions of a multihandicapped blind preschooler. This data is a portion of a study which included blind children with no other handicapping conditions.

SUBJECT:

The subject of this research is Mark, a preschool boy who was 4 years and 8 months old at the time the data was collected. Mark is blind due to congenital cataracts. He is the son of a blind father and a mother with limited vision and a physical handicap. Mark's younger sister was also blind.

At the time of this study, Mark also exhibited a severe language delay. He used a limited number of one and two word phrases, which in the preschool setting were always directed toward his "special friend", Jane. Jane was an undergraduate student in special education working with Mark as part of her course work. Mark's other forms of "communication" included screaming, babbling and hair pulling. Mark was in his second year at a university cooperative preschool which integrated handicapped and non handicapped children.

METHODOLOGY:

Mark was video taped for five days during the "free play" portion of the preschool program. These videotapes were coded according to a variation of the Flanders Interaction Analysis System. (Flanders, 1970). This variation focused on teacher verbalizations while simultaneously coding target child - per interactions.

Using this system, each videotape was coded every 5 seconds.

RESULTS:

The amount of time Mark spent interacting with peers was extremely variable over the five day period - .01 - .26. The average percentage of time spent interacting with peers was .10. Mark was involved in 42 instances of interaction over 2-1/2 hours of videotapes, and 19 of these instances of (42%) were sustained 15 seconds or longer. Interactions were almost entirely nonverbal, as Mark never verbalized to a child during the videotaped episodes and children very seldom spoke with him.

In order to look at patterns of teacher verbal behavior association with social interaction, tallies were looked at in three conditions. Teacher verbalizations preceding positive initiations. During the 25 seconds preceding initiations, teachers most often used the following verbal techniques:

- 1) indirect prompts (cues to children other than the subject as to how to interact with him) 18% of the coded intervals.

- 2) descriptions of the social setting (or "rules of the game") 7% of the time

These were the most frequently used strategies from the second category. Other frequently used verbalizations by the teacher included questions to other children (18% of the time) and reading/singing (15% of the time).

Verbal strategies which were used infrequently by teachers included direct prompts (4%), questions directed toward Mark (1%), and descriptions of the physical environment (3%).

Teacher verbalizations during periods of sustained interactions. During periods of interaction which lasted 15 seconds or more, teachers used similar verbalizations to those used preceding initiations. These included a slight increase in the use of indirect prompts (19%) and descriptions of the social setting (10%), as well as a greater number of direct prompts to Mark (7%). Reading/singing were used 19% of the time. Again, few questions were directed toward Mark, (1%), descriptions of the physical environment were limited (3%) and there was a decrease in the amount of questioning directed toward other children (9%).

Teacher verbalizations during periods involving no target child - peer interaction. During these intervals there is a dramatic change in teacher verbalizations. The use of strategies in category two which were expected to facilitate interaction decreased from 39% to 12%. Direct prompts were never used, indirect prompts decreased from 19% to 2% and descriptions of the social environment decreased from 10% to 3%. Criticism of the target child increased from 0% to 6%.

DISCUSSION:

These data, when supported by narrative descriptions of teacher verbal behavior, indicate strategies which may be helpful in stimulating peer interactions. For this language delayed, blind child activities which had significant amount of structure either inherent or supplied by the teacher and where roles and expectations were clear, were most likely to promote peer interactions. Mark was most interactive in situations where his role was fairly constant and other children could do the initiating. Such activities included "Peek-a-boo", "Ring-around-the-Rosie" and singing activities. Note the use of cues in the following situation:

Example: Jane is in the housekeeping corner with Mark and John. She tosses a blanket over their heads and says, "Somebody threw a blanket over your heads. How does it feel?" As the two boys uncover themselves, she continues, "I'm going to cover you both up with a blanket. Where are you?" During this time Mark and John are laughing continually. John continues the game by covering Mark's head with a blanket, which Mark removes, laughing.

Indirect prompts and giving directions to the target child and a peer simultaneously ("Mark and Sarah, turn the page") were likely to be followed by social interactions. These techniques seem especially critical for a language delayed blind child, who may not have the expressive or receptive skills to either initiate verbally or to understand and act on prompts designed to promote social interaction. An example of use of indirect prompts is provided in the following anecdotes:

After reading a story to a group of children, Jane says, "we've got a whole bunch of people who could play Ring-around-the-Rosie. Let's see if we can make a big circle. Everybody take somebody's hand. Ruth, you take Mark's hand. O.K. Let's go!"

Mark is in the book corner with Danny and Jane. Danny is matching a puzzle made up of a variety of textures glued to wooden blocks. Jane says, "How does that feel? Rub it on Mark's face and tell him how it feels." Danny rubs the block on Mark's cheek and says, "It's soft."

Another area for investigation appears to be the manner in which modifications of materials and teacher verbalizations interact. For example, the majority of interactions in which Mark was involved took place in the book corner. Images of two very different types of activities seemed to evolve. One was an activity in which the primary focus was on children listening to the teacher and answering her questions. The other "reading" activity involved the children actively in finding different textured pictures together and in taking turns turning the pages. Obviously, the variation in the material itself affected the out-

come of the activity in terms of interaction. However, it appeared that another important variable was the way in which the teacher structured the situation through her verbalizations to the children involved. (This was usually only a small group of children, as reading was only one of many choices available at this time).

In order to examine this difference, a sample of three episodes of story reading as compared with a sample of three episodes involving a "feel" book. The most remarkable differences appear in the amount of time the teacher used the strategies detailed in Category 2--30 percent of the time during a "feel" book activity, as opposed to 3 percent while reading other stories.

Jane is sitting in the book corner with Mark and two other children.

They are reading a book which contains textures to feel. In between reading the text, Jane says, "Can you feel the tile, Mark? It's over there where Sarah's hand is." Mark and Sarah feel the tile together.

"It's Mark's turn to turn the page--you guys could do it together."

When they get to the next page, Jane continues, "Tommy, would you like to take a turn with Mark turning the page?"

Cues to interaction were almost entirely absent during story reading.

Also, a much greater amount of time was spent in reading, per se (49 percent compared with 27 percent) during these episodes.

The only other recorded story telling episode involving Mark presented an interesting alternative to these two patterns. Unlike the episodes involving the other three stories, during which no interaction occurred, Jane's reading of "Bedtime for Frances" involved child-child interaction 12.5 percent of the time. Looking at the strategies Jane used during this particular episode, several patterns emerge. The most obvious was an increase in the use of Category 2 strategies, especially specific cues to Mark and other children.

Jane is sitting with Mark on one side of her and Alice on the other, reading "Bedtime for Frances". Jane says, "It's Mark's turn to turn the page. Turn the page, Mark." Mark turns the page and Jane says to Alice, "You know, if you came over and sat next to Mark, you two could do it together. Remember how the other day you and Mark were turning the pages together? If you sat next to each other you could do that. Should Mark come sit next to you, or will you move next to Mark?" Alice moves to sit next to Mark and Mark smiles. "Now Alice is next to you, Mark", remarks Jane, and continues to read the story.

During the story, Mark reaches out to touch Alice's hair, and his fingers tangle in it. Alice looks to Jane and says, "Ow!" Jane says, "Mark, that's hurting Alice. Alice, tell Mark that he's hurting you." Alice turns to Mark and says softly, "That hurts me". Jane remarks, "You need to touch gently, Mark". He touches Alice's leg, and Jane says, "That's right, like that". The story reading resumes.

The second noticeable difference was a decrease in the amount of time Jane spent lecturing and reading. Thus it appears that a teacher can modify an activity based upon particular material through the verbal use he or she uses to structure the activity.

Patterns which hinder interactions. Several patterns emerged which appeared to be associated with noninteraction. The most obvious was the use of criticism. It seems highly likely, however, that Mark's behavior prior to Jane's criticism was a deterrent to approaches by other children. When Mark began screaming, children tended to leave an activity. This was probably due either to the behavior itself, or to the withdrawal of Jane's attention from the group to focus on Mark. A similar loss of attention to the group occurred when Mark pulled Jane's hair. This pattern, coupled with the variability of Mark's interactive

behaviors, lends support to Kohn's (1966) thesis that the child is a primary determinant of interaction toward himself or herself.

Several times during the videotaping, Jane took Mark on an exploratory tour of the room, focusing on the names of objects and their location. Children were also named as Jane and Mark walked by. Sometimes Mark was questioned as to the name of a particular object. No child-child interactions occurred during any of these episodes. This is congruent with the increased percentage of the 2-1 strategy (describing the physical environment) in the condition of no interaction. It appears that simply describing the physical environment is not enough to facilitate interaction. This strategy appears useful only in combination with other techniques. Other teacher verbal patterns emerged from activities which seemed primarily task oriented; for example, getting Mark to sit in a chair, to hold a crayon, or to find a sponge in the water table. During this time, Jane used strings of directions and lecturing which stretched over several intervals.

Jane is at the water table with Mark. She tells him to "Find the sponge, Mark. Just like the one in our book. It's soft and squishy. Pick up the sponge."

Continued use of these types of teacher verbalizations are not associated with child-child interactions. Supporting evidence for this can be found by looking at the 41 intervals where Jane's attention is focused on Mark alone (Category 01)--there was no interaction during any of these intervals.

In similar fashion, strings of questions by the teacher, regardless of to whom they were addressed, seemed to discourage peer interaction. Questions logically lead to teacher-child rather than child-child interactions. Question asking appears particularly inappropriate as an interaction intervention strategy for Mark, as his level of language did not permit him to engage in group discussion. Obviously, its value relates to goals other than interaction, for example, the development of language skills.

CONCLUSIONS:

This study described what a teacher was saying to a multihandicapped blind preschooler in the period preceding social initiations, during sustained interaction and during periods of non-interaction. There were marked differences between strategies used preceding and during interactions and those used during periods of non-interaction. The differences in amount and type of teacher verbalizations in these conditions strongly suggest that teachers can facilitate interaction between a blind preschooler and and his/her peers.

It is important to remember, however, that the strategies which teachers use are generally linked to the goals they have chosen for a particular child. The techniques which have been focused on by this research will be important only in situations and/or programs where peer interaction is valued as an important experience for a handicapped child. Describing the social environment, giving prompts to the target child and giving indirect prompts to peers are special verbal techniques which can be used in attempts to foster interaction between blind preschoolers and their non-handicapped peers.

Table 10

Percentage of Teacher Verbalizations: Preceding Positive Initiations, During Interactions and During Periods of No Interaction for Mark

Code Number	Strategy	During Sustained Positive Interaction		Preceding Positive Initiations		During No Interaction	
		Strategy	Category	Strategy	Category	Strategy	Category
2-1	Describing physical environment	03		03 ^b		07	
2-2	Describing social setting	10		07		03	
2-3	Direct prompts	07	39	04	32	---	12
2-4	Indirect prompts	19		18		02	
3-1	Questions to target child	01		01		06	
3-2	Questions to group	07	17	05	24	02	21
3-3	Questions to others	09		18		13	
4-1	Praise to target child	---		---		03	
4-2	Praise to group	---		01	02	---	03
4-3	Praise to others	---		01	---	---	
5	Directs	10	10	12	12	15	15
6	Lectures	07		11		15	
6-0	Reading, singing	19	26	15	26	13	28
7-1	Criticism to target child	---		---	---	06	
7-2	Criticism to others	---	---	---	---	01	07
Other:							
0-1	Teacher attention on target child	---		01		04	
0-2	Teacher attention on group	05	09	03	06	05	13
0-3	Teacher attention outside group	04		02		04	
Sample intervals		135	180				376

a. Totals are rounded to the nearest percentage.

Table 11

Percentage of Teacher Verbalizations During Different Types of Reading Activities for Mark

Code Number	Strategy	"Feel" Books		Other Stories		"Frances"	
		Strategy	Category	Strategy	Category	Strategy	Category
				Total			
2-1	Describing environment	02		02		01	
2-2	Describing social environment	07		---		01	
2-3	Direct prompts	06	30	---	03	04	15
2-4	Indirect prompts	15		01		09	
3-1	Questions to target child	---		---		01	
3-2	Questions to group	09		04		01	18
3-3	Questions to others	07	16	18		16	
4-1	Praise to target child	---		---		---	
4-2	Praise to group	---		---	01	---	01
4-3	Praise to others	---	---	01		01	
5	Directs	11	11	05	05	05	05
6	Lectures	13		17		11	
6-0	Reading	27	40	49	66	43	54
7-1	Criticism to target child	01		01		---	---
7-2	Criticism to others	---	01	---	01	---	---
Other:							
0-1	Teacher attention on target child	---		---		---	
0-2	Teacher attention on group	02		03	06	05	05
0-3	Teacher attention outside of group	01		03		---	
Intervals:		151--33	include interactions	191--no intervals	79--13	include interactions	

CODING SYSTEM

1. Target child verbalization.
 - 1--to teacher
 - 2--to another child
 - 3--to the group at large or indeterminate

Teacher verbal behavior:

2. Techniques which may foster interaction.
 - 1--describes environment
 - 2--describes social environment
 - 3--direct prompts
 - 4--indirect prompts
 3. Questions (includes all questions which do not fall into previous category)
 - 1--to target child
 - 2--to a group including the target child
 - 3--other
 4. Praise or encouragement
 - 1--to target child
 - 2--to a group including the target child
 - 3--other
 5. Directs (does not include directions regarding interactions; e.g., "Go sit down").
 6. Lectures (lecturing behavior not coded in category two; e.g., discusses a topic of his or her own, or response to a comment of the child's).
 7. Criticizes
 - 1--target child
 - 2--other
 8. Other verbal behavior/no verbal behavior
 - 1--teacher attention on target child
 - 2--teacher attention on group including target child
 - 3--teacher attention on another child, another adult, her or himself, no one
 9. other coding marks:
 - denotes negative interactions
 - ¹⁰ denotes verbalizations by another child toward the target child
 - ¹⁰₂ denotes target child verbalizations in reply to another child
- Circled code numbers show when interactions with another child occur during each five second interval.

SOCIAL INTERACTION BETWEEN VISUALLY IMPAIRED MULTIPLY HANDICAPPED

INFANTS AND THEIR MOTHERS: A STARTING PLACE FOR INTERVENTION

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The process by which a mother and her infant form a nurturant relationship has received attention in recent years from several disciplines of study. Beginning with John Bowlby who first identified and defined the attachment relationship between a mother and her infant, the process has been studied as to its impact on the developing infant, the mother, and the later relationship between the mother and child. Findings from these studies have emphasized the importance of the first year to the child's later development and the significant role the mother-infant relationship plays during this formative period.

The early relationship between a mother and her infant plays perhaps an even more significant role in the development of the child with multiple impairments. As a result of multiple physical and/or mental deficits, multiply handicapped infants are often more dependent upon their mothers for providing the necessary care and stimulation, and the dependency typically lasts longer than it does for the infant without impairments.

The mother-infant relationship serves to provide multiply handicapped infants with the necessary care they need to develop, as well as the stimulation and learning experiences necessary for their physical, mental, and social-emotional development. This stimulation will need to be frequent, contingent, and multi-sensory due to the infant's inability to gain information from their environment either vicariously or on the basis of minimal cues. However, there are obstacles which must be overcome before the interaction between the dyad can provide nurturance and mutual satisfaction to the individuals involved.

The importance of the first days of life for laying the foundation for the relationship between a mother and her infant has been demonstrated through research. These first days for infants with multiple impairments are often spent in a neonatal intensive care nursery isolated from their mothers. This isolation may last days or even weeks. The longer this separation is maintained, the more difficult will be the development of a reciprocal relationship without the assistance and support from outside others.

In addition to the problems of the lack of early physical contact between the mother and her infant, the mother may experience emotional isolation from her newborn due to anxiety produced on learning of her infant's impairments. Following the initial shock and stress, the parents will usually go through several stages of grief as they move towards gradual adjustment to the reality of the long term effects of the child's multiple handicapping conditions. Each mother and father progress through these stages at different rates due to certain internal and external factors. Internal factors include specific personality characteristics, attitudes towards impairments and impaired persons, general knowledge about handicapping conditions, and financial and educational level of the parents. External factors may include the existence of support systems or extended family networks, or the availability of sensitive and competent professionals. Despite the individuality of each parent's adjustment, this period of stress can further impede the development of this vital nurturant relationship.

The process through which a nurturant relationship is formed between a mother and her infant is viewed as a reciprocal one where both members of the dyad participate in a way which facilitates interaction. Brazelton, Koslowski, and Main (1974) described the rhythmicity of this reciprocal interaction. They

concluded from their study that mothers who were successful interaction facilitators were sensitive to their baby's cues for interaction and geared their behavior accordingly. The babies that Brazelton and his colleagues observed provided clear cues and were responsive to their mother's interactions.

Mothers of multiply impaired infants are seldom provided with such observable cues. Multiply impaired infants may not respond consistently to maternal attempts to play with, cuddle, or console them. Infants with a severe visual impairment may provide little or no visual interaction with their mothers, such as eye contact, contingent smiling, or facial gestures. Infants with orthopedic impairments such as cerebral palsy may not conform to their mother's body when they are being held. A hearing impairment can obscure the infant's ability to respond to the sound of the mother's voice. A combination of two or more of these impairments can severely impede interactions between a mother and her infant by inhibiting the development of a reciprocal communication system.

Despite these obstacles two instructional strategies hold promise for facilitating the development of this important early relationship. These strategies are early intervention programs and family involvement in instructional planning.

Research continues to point to the importance of the first years of life to the overall growth and development of the individual. Specifically, during the first three years, the foundation is laid down for all future motor, language, cognitive, and socio-emotional development. It is during this time that the young child learns to respond to, interact with, and gain some control over the environment.

Intervention during these early years is critically important to the infant with multiple impairments. Due to their limited ability to gain information from and interact with their environment, stimulation and learning experiences must be provided in ways which are meaningful to them. While many effective infant and young child intervention programs exist, in most cases the persons responsible for providing effective learning experiences are the child's parents. Parents of multiply handicapped infants play an important role in insuring effective early intervention.

Parents are the infant's first source of nurturance, stimulation, and learning. With multiply handicapped infants and young children whose skill acquisition usually requires repeated practice, contingent reinforcement, and diverse instructional approaches, the participation of parents becomes even more vital. Despite the importance of the parent's role and the obviousness of a natural partnership between parents and professionals who serve multiply impaired children, this relationship has received little attention until recently and even less direct study. How can we best meet the needs of the multiply handicapped infant and young child? Perhaps the best way to support and provide services to the infant and his family is to encourage a consistent environment where the infant is provided with the necessary nurturance and learning experiences needed for optimal development.

This study begins this process by examining the social interactions between multiply impaired infants and their mothers. Observations were made in the dyad's home and in a clinical setting. Information was collected on each mother and infant, such as the mother's age, educational level, and marital status and the infant's ordinal position within the family. In addition, the amount of stimulation provided in the home environment was recorded.

The subjects involved in this study included eighteen severely visually impaired multiply handicapped infants and their mothers. The infants ranged in age from 4 to 24 months. None of the children were ambulatory and only one displayed any verbal behaviors. All of the infants and their mothers were attending an infant program which provided educational services to sensory impaired multiply handicapped children and their families.

A severe visual impairment was established on the basis of a recent ophthalmological evaluation, within one year of the initiation of the study, a functional vision evaluation conducted by a vision specialist, and a developmental evaluation conducted by a psychologist. Criteria established for designation of a severe visual impairment was that the child demonstrated no better than gross form perception throughout the evaluation process. Of the subjects, four were totally blind and the remaining 12 had limited vision.

In addition to the visual impairment, the infants selected had one or more additional impairments. The impairments included auditory impairment, orthopedic impairment, and developmental retardation. Developmental retardation or delay was defined by obtaining an overall functioning level which was less than half the child's chronological age on the Bayley Scales of Infant Development and the Callier-Azusa Scale.

The infant-mother pairs were observed in their homes and in a structured setting. Observations in the home were conducted according to an interval recording procedure over a two day period.

A procedure developed by Harriet Rheingold (1961) for evaluating non-handicapped infants was used to record observations made in the dyads' homes. This protocol consisted of a series of 10 minute observation periods with a 5 minute break in between for a total of 3 hours each day. Each minute of the observation segments was divided into 4 observation intervals. During this interval one second was used for observation and 14 seconds were used for recording behaviors observed. In a 10 minute period, 40 observations were made. This was conducted until 10 10-minute observation periods were recorded. This resulted in a total of 800 observations in the dyad's home over a two day period. Home visits were conducted on the morning of one day and the afternoon of the other consecutive day.

At the end of the second day of observation in the home, the mother was asked to complete a demographic data sheet. The sheet included information about the child's age, sex, race, handicapping conditions, and ordinal position in the family; the father and mother's age, educational background, occupation, and marital status; the approximate number of hours the father spent caring for the child per day; and the amount of time persons other than the parents provided care for the child. While the mother completed the demographic data sheet, an evaluation of the home environment was conducted using the Home Inventory (Birth to Three): Home Observation for the Measurement of the Environment developed by Bettye Caldwell. This instrument measures the quantity and quality of stimulation available to the infant in the home by evaluating the types of toys provided, the amount of verbal responsivity of the mother to the child, the restrictiveness of the environment, the organization of the environment, and the amount of maternal involvement with the child.

Following the home observations the infants and mothers were seen in a structured clinical setting. These observations were videotaped for later analysis. The room where the videotaped sessions occurred was located in a private agency serving deaf children. The room was equipped with one-way glass, a couch, rocking chair, a child's table and 2 chairs, and age appropriate toys displayed in an open bookcase. The camera and microphone were concealed from the subjects.

The videotaping consisted of two fifteen minute sessions: an unstructured period and a structured period. The unstructured period involved leading the infant and the mother into the room, helping them to get settled, and then leaving them for a specified period of time without giving them any instructions. The structured setting began when the investigator reentered the room and instructed the mother to play with her baby. Examples of play behavior were given to clarify the instructions. The mother and infant were again left alone and

taping commenced for 15 minutes.

The videotapes were evaluated as to the total number and different kinds of infant and maternal behaviors observed as well as the sequence in which they occurred during the interactional episodes between the dyad. Five minutes of each of the videotaped settings were analyzed. The observations began when interactions, other than general caregiving commenced. Observations were made for 5 seconds, the tape was turned off and the behaviors observed in the order of their occurrence were recorded. For each of the two videotaped settings, 60 5-second intervals were recorded. Timing was maintained by a prerecorded audible beep.

Behaviors recorded during the home observations and the videotaped sessions were quantified and analyzed using a Pearson Product-Moment Correlation and a t-test for correlated samples. Additionally information obtained from the Demographic Data sheets and the HOME Inventory were correlated with the mother and infant behaviors observed.

Findings of this study were organized under four research questions.

These were:

1. What were the effects of the infants' impairments on interactions with their mothers?
2. What modalities were utilized by the mothers and what was their infants' interactional behavior?
3. What internal variables were significantly correlated with mother and infant behaviors in the home and in the structured setting? Internal variables included age, educational level, and marital status of the mother; age, sex, race, handicapping conditions, and ordinal position of the infant; and socio-economic status of the family.
4. What external variables correlated significantly with mother-infant behaviors in both settings? External variables included the father's participation in caring for his infant and the existence of support systems other than the parents in providing care for the infant.

In response to the first question which examines the possible effects of an impairment on the interactional behaviors, a statistically significant correlation was found between the number of times infants visually oriented towards their mothers and the amount of time mothers spent playing, caregiving, looking at, affectioning, and verbalizing to their infants. This indicates that these mothers may have increased the number and variety of interactional behaviors in response to their infant's visual orienting behavior.

Information obtained from the HOME Inventory regarding the quantity and quality of stimulation available in the home, was correlated with maternal and infant behaviors. A significant correlation was found between infants who visually oriented towards their mothers and the Factor I. Emotional and Verbal Responsibility of the Mother. This factor primarily measures positive verbal behavior, but it also includes affectioning behavior demonstrated by the mother to her child.

The infants' use of their auditory modality to interact with their mothers was demonstrated through vocal behavior. Happy vocal behavior, which included cooing or laughing, was positively correlated with maternal instructional verbalizations which included labeling objects and activities the infant was involved with. Unhappy vocalizations, which included crying or whining behavior, were positively correlated with maternal soothing behaviors including lulling verbal behavior, stroking, and rocking.

Infant tactile behavior was defined as purposeful touching of the mother. Accidental swipes or brief unintentioned contact was not counted as tactile interactions for this category.

In the home environment, the number of times infants touched their mothers were related to maternal touch cueing which included tactile contact for the purpose of instructing, instructional verbal behavior to, and looking at their infants. A significant negative correlation was found between the number of times infants touched their mothers in the unstructured videotape setting and the amount of times mothers held their infants in the structured videotape setting. In addition in the structured setting, infants who touched their mothers were correlated with touch-cueing behavior from their mothers.

Infant tactile behaviors in the home and clinical environment were significantly correlated with factors from the HOME Inventory. In the home environment, infants who frequently touched their mothers were negatively correlated with Factor II. Avoidance of Restriction and Punishment and positively correlated with Factor IV. Provision of Appropriate Play Materials and Factor V. Maternal Involvement with the Child.

In the videotape setting infant tactile behavior in the unstructured setting was negatively correlated with Factor II. Avoidance of Restriction and Punishment and Factor III. Organization of the Environment. In the structured setting, the number of times infants touched their mothers were again negatively correlated with Factor II and positively correlated with Factor IV. Provision of Appropriate Play Materials and Factor V. Maternal Involvement with the Child.

Mention should be made of the correlational findings between the frequency of infant behaviors in the home and clinical environment and Factor II from the HOME Inventory. These findings were interesting in that due to the wording of this factor a lower score indicated a higher frequency of maternal behaviors which were restrictive and punishing. Therefore a home environment which was more restrictive and punishing was significantly related to a higher frequency of infant behaviors. This can be interpreted in several ways. Three possible ones are that 1) These multiply handicapped infants were more responsive to environments that were intrusive, structured, and more restrictive; 2) The infants were more responsive to a consistent environment in which contingent consequences were delivered, both positive or negative, irregardless of the presence or absence of the investigator; or 3) children who were functioning at a higher cognitive level and were therefore more capable of higher rates of interactional behavior also required more supervision and restrictions.

The effect of the ways in which the infants played were examined as to their relationship to maternal interactional behaviors. Infants' play behavior was examined three ways; play with toys, play with objects, and play with their own bodies.

The amount of time infants spent playing with or manipulating toys was significantly correlated with the time mothers spent playing with, looking at, tactilely cueing, and playfully verbalizing with her infant. The infants' play with objects other than toys, for example measuring spoons or a hair brush, was correlated with instructional verbalizations from their mothers.

Conversely, the number of observations in which infants were playing with or manipulating their own bodies was found to be correlated with decreased play, adjusting, and affectioning behavior from their mothers. Additionally, infant body play was related to significant periods of maternal absence. Maternal absence was defined as the mother being out of the room and out of visual contact with her baby.

The same findings were obtained in the videotaped setting for infant play with toys and objects. For the infants who spent long periods of time playing with their bodies during the videotaping, maternal verbal and tactile interaction was used to either restrain or distract the infants. A significant correlation was found between infant body play and maternal tactile and verbal interaction in response to this body play.

Infant state was observed through the infant's respiration rate, activity level, and facial expression. There were six states evaluated. State 1 was sound asleep with no movement. State 3 was when the child was waking up from a sleep and was considered to be drowsy. State 4 is a fully alert and quiet state in which the child is considered to be ready for interaction and learning. State 6 is where the child is in a full cry.

Infants who spent long periods of time in a drowsy state or state 3 were correlated only with maternal caregiving behaviors, including feeding and dressing. Infants who spent long periods of time in the alert-active state or state 5 were found to be correlated with maternal instructional verbalizations.

Two factors from the HOME Inventory were found to be related to infant state levels. Factor IV. Provision of Appropriate Play Materials and Factor V. Maternal Involvement with the Child were negatively correlated with State 3 behaviors (drowsy) and were positively correlated with State 5 behaviors (alert-active).

The infants who participated in this study were severely visually impaired and had at least one other impairment. The number of impairments each child had was correlated with maternal behavior observed in the home and clinical environments.

The number of impairments an infant had was correlated with the amount of time an infant spent on furniture other than their own beds, or in other words, out of the mother's arms in the home environment. Other positive correlations were found between the number of impairments and maternal touch-patting and adjusting behavior.

In the clinical setting which was videotaped it was found that the more impairments an infant had the fewer the occurrences of maternal verbal behavior in both the unstructured and the structured setting. Two correlations that are particularly interesting was first that a significant relationship was found between the number of the infants' impairments and maternal touching behavior in response to infant vocalizations. Secondly, the infants' impairments were also significantly correlated with the number of unhappy vocalizations by the infant following maternal touching behavior. This indicates that while the mothers were responding to their infants' vocal behavior, the mother's response may have been aversive to the infants.

The second question addressed in this study was to observe the types of modalities the mothers used to interact with their multiply handicapped infants and their effects on the infants. The modalities included visual, auditory, tactile, and kinesthetic.

The mothers' interaction through the visual modality was observed through her looking at her infant and facial gesturing. In the home environment the number of times mothers looked at their infants was correlated with happy and unhappy vocalizations by the infant, playing with toys, and touching the mother. Facial gestures by the mother were correlated with infant eating behavior.

In the videotaped setting maternal facial gesturing was found to be significantly correlated with infant vocal behavior in both settings. An increase in infant activity was also found to be correlated with maternal facial gesturing.

The mothers' use of the auditory modality was observed through her verbal behavior. Verbal behavior was divided into three categories. These were instructional verbalizations, which included labeling or describing objects or activities in which the child was involved; chatting or playful verbal behavior, including cooing, asking questions ("What are you doing?"), or repeating ("I gonna getch, I'm gonna getcha!"); and lulling verbal, which included verbal behavior in which the mother's tone, volume, stress, and elongation of syllables indicated a soothing purposes; as well as soft humming, or singing. Instructional verbalizations by the mother were correlated with the widest variety of infant behaviors. Instructional verbal was correlated significantly with infant happy vocalizations,

eating, playing with objects, looking at the mother, touching the mother, and smiling. Playful or chatting verbalizations were correlated with infants eating, playing with toys, and looking at their mothers. Lulling verbal behavior was correlated only with unhappy vocal behavior from the infants.

Maternal tactile behavior was observed through three ways: patting or stroking, cueing tactilely either by prompting or manipulating, and affectioning including kissing and hugging. Stroking or patting by the mother was found to be negatively correlated with the time infants played with toys in the home environment and looked at objects in the structured setting of the videotaped sessions. Tactile cueing which was used to structure and reinforce the infants' attempts to interact with and modify their environment was found to be correlated with the rate of infants' tactile contact with their mothers and playing with toys in the home. In the clinical setting tactile cueing by the mothers was negatively correlated with infants' unhappy vocal behaviors and positively correlated with infants touching their mothers.

Affectionate behavior which included kissing and hugging of the infant by the mother was related to infant unhappy vocalizations and looking at the mothers and was negatively correlated to the amount of time infants spent playing with their bodies in the home observations. Affectionate behavior observed in the videotaped sessions were only correlated with unhappy vocalizations by the infant.

The kinesthetic modality was utilized by the mothers in the study only to soothe or pacify their infants. This was observed in home and clinical environment by mothers rocking their infants. The significant correlation found was between maternal rocking and the unhappy vocalizations of the infant in the home environment.

The third and fourth questions posed in this study was "What was the affect of other variables both within and outside the dyad on the mother-infant behaviors observed in the home and in the videotaped clinical settings?" These variables were predetermined and obtained from a demographic data sheet which was given to the mother on the second day of the home visit. Most of the items were self-explanatory, but the mother was given brief instructions and told to ask questions if further clarification was needed. She then was asked to complete the form.

Of the maternal variables that were obtained, age and educational level were found to be significantly correlated with more of the home visit variables. In the videotaped clinical setting these two variables plus marital status were found to be related to mother and infant behaviors observed.

In the home environment a relationship was found between the age of the mother and the amount of time she spent tactilely cueing, looking at, and chatting to her infant. The age range of the mothers was from 20 years old to 38 years old.

The educational level of the mothers ranged from 5 who had not completed high school to 3 who had completed at least one college degree. The educational level was positively correlated with the time mothers spent touch-cueing, looking at, and chatting with their infants. As in the case of age, mothers with higher levels of education utilized visual, auditory, and tactile modalities to interact with and teach their infants.

In the videotaped setting the findings made in the home were repeated in regards to age and educational level, and marital status correlations were added. However, an interesting twist was found regarding the correlations between marital status and infant behaviors.

Married mothers were found to be correlated with increased rates of verbal, play, holding, touching, and looking at behaviors than were nonmarried, either single or divorced, mothers. Conversely, infants of mothers who were

unmarried spent more time cooing or laughing, looking at their mothers, looking at toys and objects, smiling, and touching their mothers than did infants with married mothers. This may have occurred due to the overstimulation of the infants by mothers who were attending to the artificial setting rather than to their babies' cues for interaction. It is unknown why this occurred more frequently with married mothers than with unmarried mothers except that the married mothers may have had someone to report to regarding their baby's performance following the videotaping sessions.

Infant variables which were used to correlate with mother and infant behaviors included age, sex, race, and ordinal position. In the home environment age and ordinal position were found to be correlated with more behaviors and environmental variables. These relationships were as would be expected in children without impairments. The older the child the less the mother was observed feeding, holding, and rocking. Infants who were first born and only children spent less time in an infant swing and were held and patted less than did the later born infants.

In the videotaped clinical settings the ages of the infants were found to be negatively correlated with maternal rocking and facial gesturing. As in the home, correlational significance was found with the ordinal position of the infant. Infants who were first born and only children received more touching, playing, and facial gestures from their mothers than did infants who were later born with siblings.

Maternal and infant variables were correlated with information obtained from the HOME Inventory. Maternal age was correlated with Factor I. Emotional and Verbal Responsivity of the mother, Factor IV. Provision of Appropriate Play Materials, and Factor V. Maternal Involvement with the Child. The educational level of the mother was correlated with Factor IV and Factor V.

The infant's age was negatively correlated with Factor III. Organization of the Environment. This finding was the opposite of what might be expected due to the belief that the older the child the more important is insuring that the environment is safe from hazards and that there are specific places for the child to place his clothes and toys. Sex of the child was correlated with Factor I. Emotional and Verbal Responsivity and Factor II. Avoidance of Restriction and Punishment. These correlations indicated that female infants received more attention from their mothers and less discipline than did male infants in this study.

The fourth question considered the effect of child care provided by persons other than the mother on the mother's behavior with her infant. Child care by others was divided into child care provided by the father and child care provided by persons other than the parents. The latter category could include relatives, friends, or support persons such as the child's teacher or babysitter. Information on father-care and other-care for the infant was gathered through an interview of the mother conducted on the second day of the home visit.

Fathers who spent time caring for their infants freed their wives for personal time and provided emotional support in caring for their multiply handicapped infant. The effect of this support is seen in the relationship between the father-care variable and increased verbal interaction in the videotaped clinical setting.

The most profound effect, however, was noted with correlational information from the other-care variable. In the home setting, the amount of time persons other than the child's parents spent caregiving was found to be significantly correlated with maternal looking at, chatting with, and touch-cueing her infant. Other-care was negatively correlated with maternal absence from her child during the home observations.

In the videotaped clinical setting, maternal holding and rocking were found to be negatively related to amount of other-caregiving. This indicates that the mother spent time performing other activities with the infant rather

than simply holding their baby and rocking.

These findings indicate that mothers who had opportunities to spend time away from their child care responsibilities, spent more time when they were with their infants interacting using a variety of modalities than did mothers who received less outside support and relief time. The importance of the availability of a support system which provides some child care is emphasized through the mothers in this study.

The results of this study have important implications for those of us who serve multiply handicapped infants and young children and their families. With improved medical technology and methods for identifying these children for service, we will be increasingly charged with refining strategies to meet the needs of this special population.

Research has demonstrated the importance of early intervention and the vital role families of multiply handicapped children play in the physical, psychological, and social development of their child. As service providers it is important that we begin to understand the family dynamics so that we may support the environment which ultimately determines the child's chances for optimum development.

In this study mothers were found to respond most consistently to visual cues from their infant. However, some maternal behaviors were related to auditory and tactile interaction by the infant. The ability of the mother to respond contingently to her infant's behaviors are crucial to the development of a reciprocal and mutually satisfying relationship.

Similarly, infants whose mothers used multisensory interactions, exhibited a larger number and wider variety of responses than did infants whose mothers interacted only by holding, rocking, and touching to soothe. The type of modalities an infant prefers for interaction should be assessed. Concurrently the quantity and salience of their behaviors should be increased to enhance the detection of and response to by the mother.

Correlational data from this study indicated that infants who spent long periods of time in a drowsy state and were more severely impaired received little maternal interaction other than caregiving and consoling. With the children in this study, as is true of other multiply impaired infants and young children, many of them were on large doses of anticonvulsant medication. The dose was large enough to render them unresponsive to the environment most of the time. The effect of this drugged condition on the interactional relationship was obvious in this study. As professionals we need to be aware of these side effects and should work closely with medical personnel in monitoring the advantages and disadvantages of high dosage on the physical, psychological, and social development of the young child.

Finally consideration should be paid to the findings regarding the effect of a support system on the mother's ability to provide nurturant care and effective stimulation and training to her multiply handicapped child. Multiply handicapped infants are dependent on their parents for most of their care and learning, but because they provide few cues and infrequent reinforcement, the task is a difficult one for the parents. In addition the child's dependency may last several years beyond that required by a child without impairments. This constant care is exhausting both physically and mentally. Parents of multiply handicapped infants and young children need opportunities to spend time away from their child. Through respite care, parents can replenish the energy and the motivation needed to provide frequent, consistent, and multisensory stimulation.

The findings of this study point to the need for a better understanding of the early relationship between multiply handicapped infants and young children and their parents when planning services for this population. Intervention must not only provide training techniques to parents, but also methods for observing their child's behavior and responding contingently to them. Likewise, training

efforts should be aimed at expanding the multiply handicapped child's repertoire of behaviors with which to interact within the environment. It is in the home that the early training and socialization process should and must begin. Therefore, a major emphasis should be on facilitating the reciprocal relationships within the family which supports and sustains this process.

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PERKINS INFANT-TODDLER PROGRAM

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The Perkins Infant-Toddler Program is located at the Perkins School for the Blind in Watertown, Massachusetts, U.S.A., and was initiated in September, 1980. Sherry Raynor, founder and President of the International Institute for Visually Impaired, 0-7, Inc., had just been hired by Perkins to initiate a Pre-school Program for three to five year olds. Services for birth to three year old children were not mandated in Massachusetts. Therefore, believing that services should start as soon after birth as a visual impairment is identified, she and her staff at the Preschool wrote a proposal to the federal government to begin services for infants. The proposal was funded, and thus began the development of the Perkins Infant-Toddler Program from ages birth to three as a Model Demonstration Project. It has been funded by the United States Government for a three year period which ends on June 30, 1983. The services developed by the Infant-Toddler Project will continue under the auspices of the Perkins School for the Blind within a birth to five year program.

The only criterion for acceptance to the Program is legal blindness, (20/200 visual acuity and/or a visual arc subtending 20 degrees with best correction) or suspected legal blindness. (It is interesting to note that in our current population, over 50% of our children are blind rather than functioning with low vision.) If secondary disabilities become apparent during participation in the Program, the children continue to be served in the Program and receive additional services as needed. Some disabilities which have developed are: seizure disorders, neurological impairments, retardation and hearing impairment.

The Infant-Toddler Program is the outcome of a philosophy which centralizes the importance of and respect for equal sharing of power between staff and families. Sharing power is often given lip service by the "helping" professionals, but the Perkins staff and parents' commitment to personal and family empowerment is continually under scrutiny and self appraisal.

The Program's philosophy is illustrated by the kinds of questions which each staff member continually bears in mind as she shares the joys and sorrows of working with blind and visually impaired babies and their families:

1. What help do I need in understanding the needs of this family
 - from the family?
 - from other staff members?
 - from medical personnel?
 - from printed material, research, etc.?
2. How can I fully understand and be empathetic to the way each child's visual disability affects the daily living experience of its family?
3. How can this particular family's style of life and home environment be respected and used to foster maximum learning?
4. How does my style of life, my approach to programming and parenting assist or detract in each parent's mobilization for meeting the needs of their visually impaired child?
5. How can parents and I openly, honestly communicate, listen and respond to each other's concerns about:
 - their child?
 - daily programming?
 - styles of relating?
 - short and long-term goals?
6. How can I assist families to affect needed change without power depriving

- and manipulative tactics, that may yield quick problem resolution, but at the expense of long-term family motivation and positive self-image?
7. How do the parents relate the center-based experiences they have to their home-based experiences? How do I relate the two experiences? Are the experiences seen the same way?
 8. How can each family and I develop a satisfying pace or rate of accomplishment together? How does each of us keep from overpacing or underpacing the other?
 9. How can parents and I openly share professional and personal records, information and materials without overestimating or underestimating parental concerns and emotional receptivity?
 10. How can each family and I develop complete trust, and share fully the responsibilities, successes and failures in a personal and family-empowering way?

Parenting any child involves a great deal of instruction but, as is very obvious to all of you, blind children require more systematic instruction than their visual peers. We maintain this must not be at the expense of a normal, loving environment with family and community members. Therefore, our Program puts central emphasis on the normalization of the parents' instructional and nurturing role rather than utilizing the parent as a "special needs teacher". As with the normal family, parental self-determination is valued in achieving the most natural nurturing family instructional environment.

The Infant-Toddler Program presently serves 17 visually impaired and blind children with the following staff: 1 coordinator, 1 head teacher, 2 teachers, 1 social worker, and 1 secretary.

Consultative services include: Audiologist, Speech-language Pathologist, Physical Therapist and Occupational Therapist. All professional direct-care staff persons have Masters degrees appropriate for their work with visually impaired and multiply handicapped children.

Being located in the metropolitan Boston area, the Program has the advantage of utilizing graduate students as administrative and teaching interns. The Boston area also affords parents and professionals the luxury of on and off-site inservice experiences. Inservice topics have included: record keeping, home teaching, neonatal assessment, sensory aids for infants, effects of having a handicapped child on siblings, emergency issues, etc. Information and material from inservices and conferences attended are shared by parents and staff who attend. We are aware that the staff ratio and amount of supportive resources we enjoy is luxurious in comparison to that of the rest of the world. Nonetheless, we feel that our experience is relevant and of value to far less advantageous situations.

Unlike home-visiting intervention programs, families are not automatically assigned a home teacher for educational assessment. During an initial visit to a prospective family's home, the Program's Social Worker gathers a wide variety of necessary data and observes the family's life style and parenting methods. Her information is shared and discussed at a staff meeting, and a collective decision is made as to who would seem to be the most appropriate available teacher for a family. A sense of collective involvement with all families is encouraged in staff members throughout each family's participation in the Program.

Physically, the Perkins staff share one room as open office space. This facilitates collective involvement and immediate communication via phone calls, letters, medical and home visits. Consequently, the elation or depression that a family or staff member experiences, has immediate outlet among personnel. Staff sharing, and their rejection of territorial ownership of families or their visually impaired child, encourages invaluable interchanges and open suggestions between personnel. It restricts ego inflating temptations which encourage family, parent and child dependencies upon any single professional staff person.

The common attitude of many programs that parents should relate to early intervention services through a single person, is viewed by our Program as a control issue. We have found that our staff members, who are secure with a parent empowerment philosophy, are sensitive to the growing edge of family needs. If error is to be made in relating to those needs, it is preferably in the direction of too much family responsibility rather than in the direction of infantilizing constriction.

In developing the Infant-Toddler Program, we try to represent one alternative to the developed countries' customary intervention approach using a transdisciplinary model. Transdisciplinary models funnel information through a single primary professional team member to the parent. In our Program, the PARENT IS the PRIMARY team member. The parent has the responsibility for key decision making and follow through.

Parents are not isolated in decision-making responsibilities. As members of a team, they do receive ongoing input and support from other team members. Thus far, this approach has been affirmed by staff and parents as having a most family-empowering effect.

How do we get to this stage with parents? The early reactions we, and we are sure you, have experienced from parents of blind children, are their requests for instruction and direction. Too often, these requests are a subtle (sometimes a not so subtle) transfer of responsibility, by parent to professionals, out of a natural sense of parental grief and inadequacy. To accept such a transfer professionally, in our opinion, is self-serving and ego enhancing; it enforces learned helplessness, (or to use Lilli Nielsen's apt term "TAUGHT" helplessness), reactions in families. Responding to requests such as, "Please tell us what should we do with our blind child?"; "Where do we begin to cope?", at the outset of our work together, we assist parents in recognizing that they are already engaged in a process of learning what they should do and they have begun to cope. Their rightfully sought after answers are emerging in this process. Neither we nor they create the process, but together we can clarify answers which are latent within it. From the beginning, we assure parents that we and they can use developmental and assessment tools, research and observation to direct a programmatic response for their child in their process. We thereby reinforce each other in mutual recognition; as in the words of the poet Theodore Roethke, "We learn by going where we have to go".

No role is predetermined in determining how to provide the best means for each blind child's essential skill learning. However, the positive effect of the bond between parent and child is our first means for selecting intervention techniques. It is supplemented by the affect of brothers, sisters, grandparents, extended family members, neighbors, friends and community. The potential within the child's surrounding environment is constantly and carefully considered by teacher, social worker, and parent in developing specific program activities.

Each week the family's ongoing and changing dynamic has affected the visually impaired child's learning in some way. It may be the result of activities systematically encouraged by following a written weekly home activity sheet designed by parent and/or teacher, or it may be the result of spontaneous interventions by family, friends, neighbors or community. Either dynamic when effective is encouraged, recognized and valued in our teaching program.

Assessment and curricula tools are used by parents as well as teachers as a resourceful response to the question, "What are appropriate developmental alternatives to utilize for a visually impaired child?". The tools are appraised in response to a second question, "How realistic are the goals for this particular visually impaired child?" -- considering the child's cultural, economic, ethnic and religious family life. The population we serve does cover a broad spectrum of economic, educational, cultural and ethnic strata. We emphasize that for this age group, parent and professional observation and sharing is as important, if

not more important, than formal assessment and curricula tools as a basis for developing an adequate individualized program.

The goal of maximizing family ownership and parental confidence in coping with their visually impaired child's educational needs is geared to prepare the family for smooth transition into the Massachusetts state mandated (age three) public system for special needs children. Prior to this transition, care is taken to share with parents the resources and legal information available to assist in ongoing self-determination within the larger system. Although official contact with our Program ends within a three-month period of transition, staff and parents do have occasional contact and communication beyond that time. Parents are welcome to continue to join the Infant-Toddler weekly or monthly parent group for as long as they desire.

Our parent support group, like every other dimension of our Program, does not originate with the professional staff. The parents determine the curriculum, and it reflects the current needs of those involved. In the past, weekly daytime meetings emphasized educational information about blind development, benefits, medical interventions, etc. At present, there is greater desire for, and emphasis on, mutual support in weekly meetings. Educational meetings are still requested, and are scheduled primarily for monthly evening meetings.

Parents have provided for each other a dimension of sharing which professionals cannot embrace. By supplying an atmosphere in which open, honest sharing and support can take place, and in which parents determine the "way to go", we have sustained a good level of parent attendance and interest.

Parent involvement in the Institute for Visually Impaired, 0-7, Inc. has resulted in Infant-Toddler Program parents testifying at legislative hearings, speaking at state conferences and at this conference in Aruba. The amount of active parent commitment reflects the feeling that by sharing power and realizing their potential, parents are free to look beyond the needs of their own blind child to the overwhelming needs of blind children everywhere. As one mother said, "Realizing the pain you have felt personally, you have to think of others in the same boat."

We are pleased at the quantitative involvement of our staff and families with visual impairment related issues. But, we believe the qualitative contribution our parents have made to the Infant-Toddler Program itself may be as important, if not more so. They formally and informally critique teachers, staff, center-based program and physical environment. They have affected meaningful, substantial changes in all areas of planning and programming. Our trust in the value of parental critique and parental power, and in our ability to free ourselves of the confines of professional ego tripping, is reflected in a recent parental comment. After sharing their primary assessment tools, a number of medical and progress reports, the parent put her arm out to clap the teacher's back and said, "I trust you. You treat me as equal." "Nobody never gave me nothin, except you." Up to their child's enrollment in our Program just a few months prior to this comment, this parent had felt defeated, angry, helpless and depressed. Her child's progress blossomed as the parents gained confidence and power.

There is a unique aspect of the Infant-Toddler Program offered at Project expense which we feel is of enormous value. A medical developmental evaluation is offered annually to Program families. It is coordinated with a pediatrician, physical therapist and teacher at the University of Massachusetts Medical Center. Most families and programs have numerous ophthalmological, neurological, genetic and other reports. However, no one ties all the reports together to fill in gaps and explain the significance in understandable terms to program professionals and parents. The process of gathering information for this evaluation, and the evaluation itself, provides our staff and parents with good focusing time. Recommendations from these evaluations have been far reaching

and useful to both families and staff.

It is true that the Infant-Toddler Program is unusually fortunate in having optimal educational, financial, medical and professional resources. But, our model's viability is not dependent upon these elements. Our Program model should be and can be adapted to far less affluent and professionally-serviced situations because its philosophy provides the Program with a basic design which is, by its nature, adaptive.

The value of our home-like center environment translates to every culture. It need not be costly or idealized (as our adaptive environment slides illustrate). Its emphasis is on the center programs' representation of the style of life of the population served. Another program using this model, but reflecting another population will, and should, look entirely different. The importance lies in the immediate usefulness for the daily lives of the visually impaired children and families attending.

The appreciation and training of volunteers, siblings, extended family and community in partnership with parents and staff is a vital component of our program. Its affirmation provides a ready supply of ongoing communal resources and energy.

We believe our approach has the promise of relieving overburdened professionals in understaffed situations. It maximizes the input, training and follow-through of the individual family and their community. We have found this approach does maintain educational integrity even though the population served fluctuates. The fundamental and crucial ingredient is constant referral to our power-sharing philosophy. The Perkins Infant-Toddler Program for the visually impaired and blind centers on a vital principle: the principle of personal and family empowerment.

CAMP ACHIEVEMENT:

A PRESCHOOL CAMP FOR THE VISUALLY HANDICAPPED

AND THEIR PARENTS

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Camp Achievement is a six day residential workshop for preschool age visually impaired children and their families from around the state of Florida. It originated in 1972 as a community action project to meet the needs of the preschool blind for developmental stimulation and parent training. By that time, research had documented the need for early intervention in order to prevent serious behavior and development problems in the blind child. However, few educational opportunities existed for the preschool population and the parents played a crucial role in their child's development. Camp Achievement was therefore founded on the premise that early intervention can significantly reduce the negative connotations of blindness and can greatly improve the chances of these children developing their potential.

The pilot project in 1972 was originally known as "Camp Challenge" and was held at the Easter Seal Society camp of the same name. This was a cooperative effort of Florida State University, the Division of Blind Services and the Easter Seal Society. Professionals from around the state, teachers of the visually impaired, university students, parents and children were all brought together to plan meaningful futures for these children. In 1974, the Division of Blind Services was requested to assist with the cost of the program and has assumed primary responsibility for funding and administering the program since that time. In 1978, we moved the program to the Florida Lions Camp and adopted the title of "Camp Achievement".

The workshop continues to be held twice a year, usually in March and October, at the Lions Camp in central Florida. The camp is owned and operated year round by the Florida Lions Club. During the summer, the Lions also offer a free two-week camp experience for older visually impaired children. In keeping with our informal approach to learning, this is an ideal setting in the middle of 40 wooded acres, with a lake for boating, an olympic size swimming pool, a large gymnasium, horses for riding and nature trails for the blind.

Families are referred from around the state by their Division of Blind Services Children's Counselor. The only eligibility criteria is that the child be severely visually impaired and under the age of six, although we do accept older multihandicapped children and their families if they have never attended before. The majority of these children are experiencing developmental delays and many have additional handicaps such as cerebral palsy and chronic health problems. Some are enrolled in educational programs and some live in very rural areas where no services exist. Twenty-five families are considered maximum, but the average attendance is twenty-one. The program begins Friday afternoon and ends Wednesday, thereby allowing many working fathers to attend for at least the weekend. Both parents are invited to attend but at least one parent or guardian must accompany the child.

The purpose of the program is actually threefold: to provide direct services to preschool age blind children and their families; to serve as a resource for parents and professionals; and to provide practical experience for university students majoring in visual disabilities and related areas (Maron, 1977). However, the parents and children are our number one priority. The staff totally commits themselves to providing a warm and supportive atmosphere for

learning and sharing.

Our goal then is not only to increase parents' awareness of their child's developmental needs but to provide supportive counseling to facilitate their adjustment. Parents of blind and multihandicapped experience a variety of emotions that affect the way they interact with their child and can have long term effects of the child's level of adjustment. They may feel that the child "lacks value" because he differs from the ideal child they expected (Gardner, 1982). Their guilt or anxiety may cause them to be over-protective or have unrealistic expectations. Since medical treatment can rarely cure blindness in infants, in essence, it becomes a "parent's problem rather than a child's problem", (Scott, 1977). What the parent needs, in addition to knowledge, is the opportunity to ventilate and clarify his feelings and to receive support for the legitimacy of his anxiety.

Coming to Camp Achievement and having staff interact with the child may be a profound experience for some parents. Perhaps for the first time, people are showing that they can accept the child regardless of the handicap. They will talk to him, hold and admire him, and appreciate the child as a person who has worth.

The philosophy at Camp Achievement therefore stresses the fact that a blind child is a child first, with needs similar to all children. It is the differences that must be addressed through systematic learning. By preparing parents for the differences in the child's development and stressing the need for independence, we reduce the parent's anxiety and diminish their over-protective tendencies. We build on strengths, not weaknesses. The parents are shown, through lecture and example, that there is hope.

The first day at Camp, you find parents, students and new staff looking rather lost, not knowing what to expect. Within a day or two, you notice a change in the atmosphere as we all begin to realize the commonality of our purpose in working toward the benefit of these children. Staff and parents are housed together in large cabins and all meals are served "family style", which further contributes to the familial feeling. Friendships flourish, feelings of frustration and hope are exchanged, and attachments develop between staff and families. Very simply, we all become involved in a very unique learning experience.

PARENTS' PROGRAM

Camp Achievement is composed of two distinct but simultaneous programs: a guidance and counseling program for the parents and an educational program for the children. The parents' program consists of a series of lectures and demonstrations by professionals from a variety of disciplines and settings. We do not pay consultant fees and all of our speakers donate their time to make these presentations. Topics address such issues as educational and community resources, child growth and development, psychological implications of blindness, and more specific areas such as dressing and feeding skills. For example, a pediatric ophthalmologist travels 90 miles to make a presentation on "Common Eye Diseases in Children". This is a favorite topic for the parents as they have so many questions. The Statewide Vision Consultant from the Department of Education usually informs parents of the educational rights of their children and the availability of school programs. A few of the well experienced preschool vision teachers give seminars on self-feeding and dressing skills, as well as sensory stimulation activities. A physical therapist may lecture on motor development and provide additional suggestions for handling the multihandicapped child.

The Visual Aid Volunteers bring handmade toys to distribute and provide parents with directions for making them at home. We have an orientation and mobility demonstration under blindfold, and demonstrate a wide variety of aids and appliances for the blind. Too, some of our staff and guest speakers are blind

and one of them usually makes a presentation entitled "Growing Up Blind". Their very presence at Camp provides a role model of a successful adult which help motivate parents to work with their children.

The first evening of the program, the parents attend a short orientation and then break into the small groups to meet the staff to which their children have been assigned. We have them tell us a little about themselves and their child, as well as their expectations for Camp. We treat the parents as our "resident experts" and ask them to assist in completing a development checklist. This makes them a little more aware of development sequences and gives them an opportunity to express their concerns.

Another important aspect of the program is the group therapy and peer counseling. We divide the parents into two groups based on severity of their child's handicap. Parents of multihandicapped children may have very different concerns than the parents of the blind or visually impaired. Studies of the parent support group at Perkins Institution for the Blind revealed that through group therapy, people will accept help that they would be hesitant to accept on an individual basis (Marshal, 1947). The group identification allows them an emotional release by providing opportunities to ask questions in a sympathetic and non-judgemental atmosphere. All parents attend the majority of training sessions together, but are divided into groups occasionally for such things as counseling sessions, school visits and presentations on stimulation activities.

Parents also attend evening programs, while the staff babysits with the children in their cabins. This also provides the staff with a closer look at the child's daily routine. One of the most controversial and yet popular programs is the group counseling session. Parents are encouraged to talk about their feelings and are usually very open in discussing their fears and frustrations amongst themselves. Other evenings, they attend a movie festival, make craft projects, or join in a campfire "sing-a-long". Recently, we initiated a "free night out" where parents go into town for the evening to get a pizza or stay at camp just to socialize.

In addition, parents visit a local public school program where they observe a vision resource room or a multihandicapped program, depending on their child's needs. This provides them with a reassuring view of the types of programs available once their child reaches school age.

Besides information, we feel the parents also need an active learning approach and we therefore schedule different times for parents to observe staff working with the children in order to learn methods and ask questions. Throughout the day, parents are kept informed of their children's progress and suggested activities to prompt their development. At the end of Camp, a development report is written with specific recommendations for activities the parents can continue in the home. The report is then sent to the child's local DBS counselor who has responsibility for follow-up with the parents. If the child is enrolled in a program or is receiving home-bound training, the report is also shared with the teacher.

CHILDREN'S PROGRAM

While the parents are attending the seminars, children attend a separate program and participate in a variety of structured activities on the basis of their abilities. The children are divided into five groups on the basis of their developmental levels. Children range in age from as young as 2 months to 6 years and the average age has decreased over the years so that as many as half the children may be under two years of age. Each group is staffed by one group leader, two teacher consultants (who are either certified vision teachers or DBS Children's Counselors) and three university students so that there is a one-to-one

ratio. This ratio is necessary because of the young age and developmental delays of the children, as well as the fact that we move to different activity areas throughout the day.

The children's day is structured into four basic activity sessions from the hours of 9:00 a.m. to noon and 2:00 p.m. to 5:00 p.m. The sessions are designated as swimming, music, sensory stimulation and motor development but many other activities are included and each is individualized for the child. The higher functioning children may be working on school readiness skills or refining gross motor skills. For some others, the program may include learning to crawl or mastering self-help skills such as toileting, feeding and dressing. For still others, it may involve learning to focus attention and make basic responses to stimuli. When weather permits, swimming is the highlight of the day and often elicits more response in children, especially the multihandicapped, than any other activity. We have a Water Safety Instructor at the pool who teaches parents and staff how to orient the children to the water.

The older children also participate in an arts and crafts program where they make collages, work with play dough, bake cookies or finger paint with pudding. For gross motor activities, the children use the various equipment on the grounds such as the swings, jungle gyms and trampoline. The staff takes the children on nature walks and has them tactually explore all the elements. Throughout the day, we are continually assessing the children and experimenting with different approaches. We also try to generally assess the child's vision and we stress the importance of utilizing residual vision.

In spite of all the planning, we still find it difficult to stay on schedule and must remain flexible. Many of these infants and young children have never before been separated from their parents; some sleep most of the day; some have colds and can't go swimming, etc. Frequently, children are unresponsive or defensive to sensory experiences. Although we had guidelines and a lot of expertise, we soon learned that designing a program for each child requires a lot of trial and error. In many cases, it may take the entire five days just to begin to know the child and realize his potential. Education of the blind and multiply handicapped child of preschool age is a relatively new field which must draw its knowledge from a variety of approaches to learning. Experimentation is the key. As a result, the staff probably learns as much as the parents.

Possibly the largest barrier to our work with these children is the over-protectiveness of the parents. Their guilt or concern for their blind child often produces a very permissive attitude which interferes with the child's development. What the parents must understand is, if they want their children to act "normally" as possible, that they must expect normal behavior, within reasonable limits. One of the major goals of the parent education program is to enable parents to understand the child's need for independence and normalcy. This is an extremely difficult task for some parents. We've found it helps to have a professional require the parent or "give permission" for him not to do things for his child. A good example of this was the self-feeding program initiated by Staff at Camp. Parents had spoon or bottle fed some of the children even until age three or four. Parents would acknowledge the need for independent feeding but could not take the first step. They watched, sometimes in agony, as a staff member would require the child to hold the spoon or eat textured table foods. Mealtimes at Camp are quite an experience: food everywhere, the noise very unappetizing, but worthwhile. In just five days, we see more progress in feeding skills than perhaps any other area. The successes achieved at Camp are a continuing source of motivation for parents to continue the training once they return home.

By the third day of Camp, you can feel the sense of community, almost familial that has evolved. On the last day, almost everyone is saddened by the end of this unique and personal experience. Names and addresses are exchanged and

friendships are sealed. More importantly, however, there is a renewed sense of hope among parents. There is a significant change in parents' attitudes toward their children and toward their own abilities to meet their child's needs.

REUNION

In 1982, as a result of numerous requests by parents to return to Camp, we began a weekend "Reunion". Twenty-five families attend this weekend session which is held only once a year. Parents may return to the week long program on a space available basis, but most don't feel the need to repeat six days of training. The Reunion is therefore much more informal with fewer speakers and much more leisure time for parents to spend with their children and each other. The cost of the three day program is around \$3,000.00. We have received such positive feedback from the parents that we hope to continue the Reunion as long as it is financially feasible.

FUNDING

The pilot projects in 1972 and 1973 were sponsored by the Easter Seal Society, a non-profit organization serving the physically handicapped child. In 1974, the Division of Blind Services assisted with partial costs of the program and has assumed primary responsibility for the funding of Camp Achievement since that time. When we moved the program to the Florida Lions Camp in 1978, the Lions agreed to support our program by deducting 40 per cent from the total bill.

After the 40 per cent deduction, actual cost to the Division of Blind Services is approximately \$7,000.00. Considering the fact that as many as 95 people attend this six day program, nearly half of the expense is for food service and maintenance. The remainder of the cost is for insurance, supplies, rental of cribs and highchairs, travel reimbursements for staff, and salaries for the cooks, nurse and Lions Camp Administrator. A small part of our costs, but a great source of enjoyment for the families, is the "Camp Achievement" T-shirts provided for each child. For each six day session, the average cost per child is \$300.00 to \$400.00, depending upon the number of children attending. That's a small price to pay considering the long term benefits. The only cost of families is \$10.00 registration fee, which serves as a commitment on the part of the family.

These expenses were previously paid out of our statewide client service funds allocated by the state. However, in 1982, we experienced severe budget cuts and had to find other alternatives. Fortunately, we were able to receive a grant from our Donations Fund for all sessions in 1983.

STAFF

All staff at Camp Achievement give of their time and energy at no cost to the Division of Blind Services. This may be one factor that contributes to the success of the program because only truly interested students and professionals volunteer to attend. The staff consists of teachers of the visually impaired and teachers of multihandicapped from county school districts, Children's Counselors from Blind Services, and students from Florida State University and the University of South Florida. The statewide Supervisor of Blind Services is responsible for overall planning and administration of Camp Achievement. We do employ a full time registered nurse because of the chronic health problems of the children.

Camp Achievement offers a rare opportunity for teacher trainees to gain experience with the preschool blind child early in their careers and to relate these experiences to their classroom learning. In cooperation, the Universities give one credit hour for this practicum experience. Also, many practicing teachers of the visually impaired have not had any experience with the preschool age

child and no Florida state university offers training in that area. With the advent of Public Law 94-142, some vision teachers are now being required to work with preschoolers as the school districts are extending their services to this population.

All staff members arrive at Camp a day early to participate in a training program covering camp orientation, sensory stimulation, motor development, feeding skills and report writing. These training sessions are conducted by the Program Director and experienced staff members. A professor or doctoral student from Florida State University Visual Disabilities Track usually acts as Director of the parent and teacher training program. Additionally, the Group Leaders provide ongoing training throughout that week. Case files are available to familiarize staff with the social, educational and medical history of each child.

EVALUATION

In the past, an open-ended questionnaire was used to formatively evaluate the program and provide suggestions for program planning. This year, a summative evaluation was developed by one of the Children's Counselors with the Division of Blind Services, who is also a doctoral student in Educational Evaluation. Instruments were developed and used to evaluate parental feelings, parental educational needs, and the effectiveness of the parent education program.

Generally, the results showed that the topics identified by parents as important educational needs are being addressed in the parent education program. The only topics identified as educational needs by the parents but not covered in the parent's program were the areas of self-concept and social development. There were found to be major differences in the identification of the educational needs of parents of blind children and those of the multihandicapped children in the areas of motor development and adapting educational materials. On the affective measure, which was administered at the end of Camp, the level of parental acceptance of their child's handicap was found to be generally positive, although all parents scored low enough to be considered poorly adjusted.

Overall, the parents rated the parent education program as very effective in helping them to understand their child's needs. The only negative findings addressed camp accommodations such as the food and the uncomfortableness of the conference chairs. However, as one parent stated, "The food could be improved but that's not what we're here for."

SUMMARY

Camp Achievement continues to be a tremendously valuable program in spite of the recent increases in educational programs for the preschool age blind child. There are currently about 300 preschool age (0 to 6) visually impaired children in the State of Florida, but many will not be eligible for specialized educational services until they are three or even five years of age. The philosophy of Camp Achievement recognizes the fact that the family is the most influential factor in the child's development and, therefore, provides intensive training and supportive counseling for the parents soon after the child's eye condition has been diagnosed. It not only serves as a continuing educational resource for the parents, but it promotes positive attitudes and constructive goals for the future.

In addition to the parent education, the uniqueness of Camp Achievement offers many other advantages. The twenty-four hour observation of the child's daily routine provides new insights into the family situation and reduces the professional isolation of teachers in the field. It provides a rare opportunity for students to receive supervised training on the preschool level. It offers a chance for professionals from a variety of disciplines to pool their resources and share ideas.

Overall, Camp Achievement is a very personal experience that affects the lives of everyone who attends. The dedication and courage of these parents is a source of inspiration to us all. The all volunteer staff gives tirelessly of their time and energy and becomes genuinely involved with these families. In turn, parents receive rewards that most parents take for granted when a baby smiles or takes his first step. We all leave Camp with a sense of achievement and enthusiasm about the future.

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THE TENDENCIES IN THE EARLY EDUCATION OF THE PHYSICALLY AND
MENTALLY DISABLED CHILDREN IN JAPAN - VIEWED FROM THE
VISUALLY DISABLED CHILDREN

Hideo Ogamo
(Japan)

- (1) Problems concerning the treatment and training in the early education of visually handicapped children.

The actual status of early education of visually handicapped children started in the establishment of kindergarten within the school for the blind. Nearly half of the schools for the blind all over this country are provided with kindergartens where mostly 4 or 5 year old children are receiving education. Three year old children are gathered at the school about once a week under the name of education counselling to their parents. Only one school for the blind having been established and in function in each prefecture, not all the visually disabled children are given opportunity to receive education. In some schools teachers visit for education, but there are many things yet to study hereafter.

As for the visually disabled children of 3 or less years of age, very few schools for education are in existence throughout the country. Only in Tokyo, Tokyo Metropolitan Welfare Center for the physically and mentally disabled persons gives education to the children from 0 age on. There is hardly any prefectural government in Japan that is conducting similar education to that of Tokyo. Something like volunteer activities exist, but these must be studied more in the future. Table 1 indicates the number of visually disabled children by years of birth in March, 1983.

The contents of the education for the visually handicapped children mainly consist of sensuous training, walking exercise, daily living capacity training in addition to the fundamental education to the blind school such as speech training, play and experience instruction.

As in the normal kindergarten, the kindergarten in the school for the blind gives education to the children mainly along the six subjects (health, society, nature, language, musical rhythm, picture drawing). However, the actual situation is that the teaching on the fundamental life must be given, because hardly anything has been done at home for these children.

- (2) Early findings of the disabled children and the measures to take for the situation.

Back in the years prior to the Second World War, physically or mentally disabled children were found by a few physicians (mostly child specialists) and some psychologists through their private medical or educational counsellings on babies and infants. Later in 1947 public activities for child counselling started, when Child Welfare Law was enforced and a child counselling system was established in each prefecture. In post-war Japan, a large number of private counselling organizations were gradually founded which the parents of the disabled children could make much more use of for judgement and diagnosis than before.

The positive measure of the government for the early discovery of the disabled children started with the health examination of the children of 3 years of age at each public health center, which was put in effect by the law in 1961. In 1965, Maternal and Child Health Law was perfected. Further in 1966, general

instruction was given from the government as to the health examination and hygiene of mothers, babies and infants. In and after 1968, health examination of the 3 year old children became to be performed with an emphasis on their mental development. In 1969 on, more detailed health examination was conducted mainly through the child counselling system. Thus, the measures have been conspicuously strengthened.

Since 1973, the health diagnosis of 3 year old child became conducted at public expense, and in the same diagnosis, post-examination following the minute check, urinal as well as audio-visual examinations were additionally performed. In 1973, a general health examination of a baby was conducted once in any medical institution, while it became twice in 1974. At present, medical institutions, child counselling offices, physically and mentally disabled center, etc. are all in service to find early any disabled children.

(3) Right kind of early education

Following considerations are to be given to the visually handicapped.

1. Actual conditions of early education

The number of schools for the blind (including branch schools), provided with an elementary school in Japan counted as of 1982 was 45 out of 68, where each had a kindergarten, and the total number of classes was 72 altogether. Almost 4- or 5-year old infants are enrolled in these classes. Most of the schools for the blind, whether kindergarten is attached or not, give consultation and advice on early education starting as early as possible.

On the other hand, there are welfare centers coping with the matter of early education for the visually handicapped children as facilities independent of the schools for the blind. But only 10 or so welfare centers have been in function. People come to these centers for counsel and advice on the children starting in babyhood. The number of visually disabled children attending kindergarten or nursing schools is in the increasing tendency of late.

2. The importance of early education

The visually handicapped children are gravely influenced by the externally collected data. Unless properly treated and correctly trained in the course of nursing care, various problems occur in connection with their growth with respect to interest and concern with the outside world, positive action to any objects, imitation of movements, understanding of space relations, and the recognition of the relation between the words and objects and phenomena. Herein lies the importance of early education where desirable growth and development is aimed at by providing appropriate instruction and help suitable to the characteristics of the visually handicapped children, furnishing therefore ideal circumstances and assuring them a full babyhood and infancy.

3. Early education for children 3 or less years of age

The early education for the visually handicapped children 3 or less years of age is mainly conducted by giving advice to the protectors as to how it should be done so as to realize a full home education. Instruction on the following points based upon the action observation and development of the visually handicapped children is given. (a) Reeducation of mental burden of the protectors, (b) Acknowledgement and understanding of the protectors concerning the disability, (c) Understanding and cooperation of the family, (d) Mastery of a technique of nursing the child, (e) Provision of circumstances suitable for child growth, (f) Proper actions (seeking for outside world, recognition of the relation between the words and objects and phenomena, development of social nature, walking, exercise and physical behaviour, etc.). Such instruction is

currently available in the schools for the blind as a part of educational counselling as well as through some welfare centers. Only a few places are systematically in function.

As a problem for the future, cooperation between the special education center and kindergarten in the school for the blind, so as to make it possible to give a full function of educational counselling, to visit home when necessary, and to properly train the protectors needs a careful attention thereunto.

4. In the case of children 3 years of age up to school age

(1) Children in the kindergarten of a school for the blind

In addition to the education outline for kindergarten, instruction related to the visually handicapped children is given along the lines as follows: (a) How to promote walking capacity, (b) How to advance the working ability, (c) How to train fundamental manner of life, and (d) How to let them understand the relation between the words and objects and phenomena. The kindergarten in the school for the blind, conducting the above-mentioned instruction is discharging a highly important responsibility as an educational institution for the visually handicapped.

It is, however, admitted that a number of children enrolled in the kindergartens is comparatively a few on account of some reasons as follows.

(a) The number of visually handicapped children complicated with medium or heavy mental weakness is extremely limited, (b) Geographical distribution of these visually disabled children makes it tremendously difficult to go to a kindergarten for education, (c) More visually handicapped children attend ordinary kindergarten and/or nursing school.

The kindergarten connected with the school for the blind finds it hard to gather a group of children same age and same level of development. It may be necessary for the kindergarten in the school for the blind to get a proper group through the negotiation with the local kindergarten or elementary school and possible exchange of low grade pupils between, of course, depending upon the conditions of the district and the schools.

The following suggestions may be studied hereafter for the more complete building up of the education of the kindergarten in the school for the blind.

(a) In a prefecture where there is no kindergarten in the school for the blind, under the circumstance the visually handicapped children have no opportunity to receive education until they enter the elementary school, there should be a consideration given to the establishment of a kindergarten in the school for the blind. (b) Where there is a kindergarten in the school for the blind, more complete method for instruction should be designed so that suitable groups may be composed in the ways mentioned above.

(2) In case of a Kindergarten

The number of kindergartens allowing the enrollment of visually handicapped children is on the increase annually. If they carelessly admit the children without knowing their actual status of disability, however, not only a proper type of instruction for the visually disabled children is hopeless, but also these poor children may receive damage in development becoming isolated from the group.

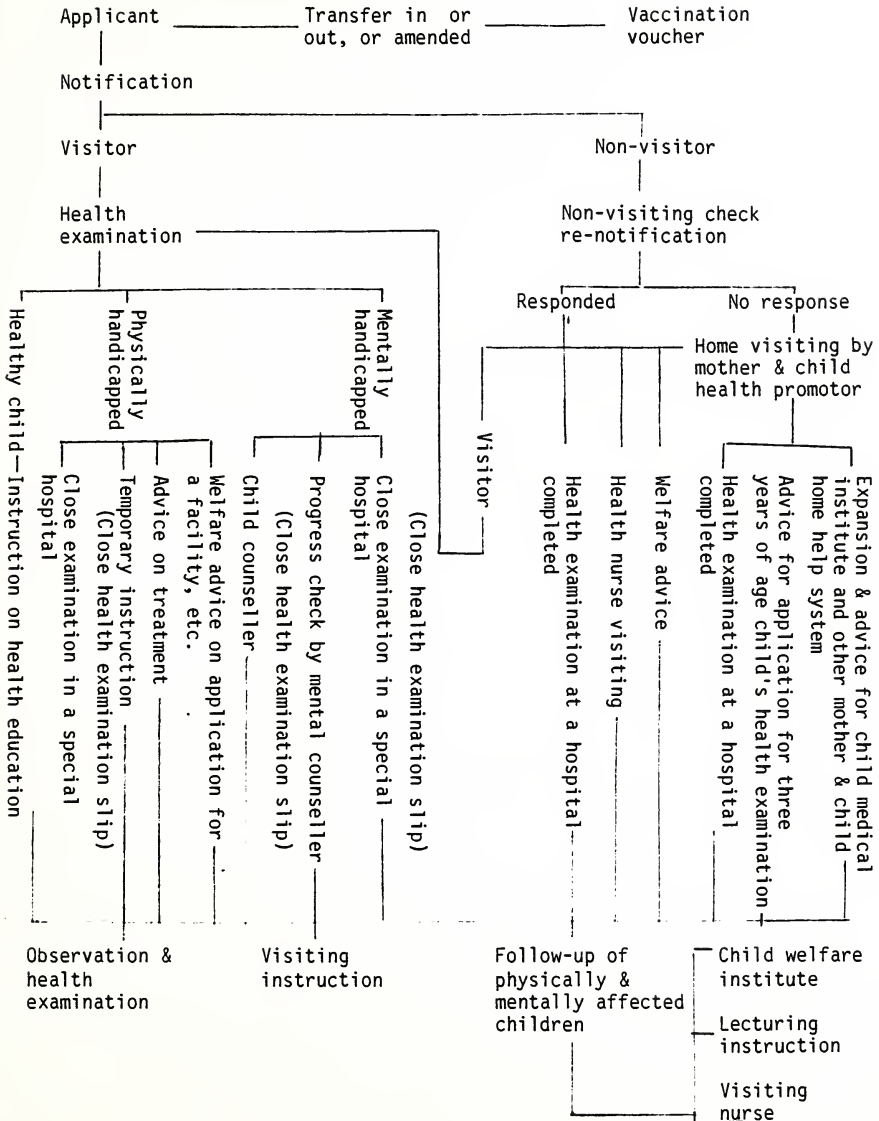
In the education of the visually handicapped children in the kindergarten, careful attention should be given to an appropriate education to the characteristics of the disabled children, with the following points in consideration. (a) Through the cooperation between special education center and the kindergarten in the school for the blind, systematic lectures and supply of teaching materials may be worked out for the kindergarten. (b) The teaching

staff may be quantitatively improved, when necessary, and their qualitative promotion may also be accomplished by means of study courses in practice.

Table 1 The Number of Visually Handicapped Infants

			<u>1970</u>	<u>1975</u>	<u>1978</u>	<u>1979</u>	<u>1980</u>	<u>1981</u>	<u>1982</u>	<u>Total</u>
R	L	F	26	8	8	2	6	1	2	133
Cataract			8	3	2	3	3	2	0	51
Opticatrophy			5	3	5	1	1	0	2	37
Microphthalmia			5	4	3	3	4	1	1	45
Buphthalmia			2	2	2	1	1	2	0	22
Retinoblastoma			3	5	1	2	0	1	0	24
Others			12	6	8	5	6	1	2	97
Total			61	31	29	17	21	8	7	409

SYSTEMATIC DIAGRAM OF HEALTH EXAMINATION FOR THE CHILDREN OF THREE YEARS OF AGE



ASSISTANCE FOR BLIND CHILDREN (ABC) IN BRIEF

Barry Bakht
(Bangladesh)

In almost all the developing countries, only a small fragment of blind children receive any kind of assistance. This is a tragic situation, because in such countries, the blind child is often the most vulnerable, the most neglected and most deprived of all the children. The situation of blind children in Bangladesh is no exception to it.

Bangladesh with a population of 90 million and having a space of 55,000 square miles, is basically an agrobased country. Naturally, the economic condition of the country is very poor compared to the total population of the country. As a result, 90% of the people are living below the average living standard. This has resulted in higher incidence along with other kinds of disabilities.

It is shocking to note that there is approximately one million blind in this most densely populated and poor developing country. 50,000 more are going blind every year, which shows 4,167 every month and 137 every day (Source IAPB Report 1980). The problem is, no doubt, gigantic and it is also gratifying to note that Government along with other national voluntary organizations, working in Bangladesh, are doing their utmost, rendering service to the curable blind. But unfortunately, the total of visually handicapped persons are not receiving any meaningful assistance, not to speak of the blind children.

Considering these hard facts, a group of likeminded social workers met at the office of Dr. Michael H. K. Irwin, the then UNICEF Representative in Bangladesh and resolved to establish an organization to be called "Assistance for Blind Children (ABC)" and accordingly ABC was formally established on April 2, 1978 with the following objectives:

- a) The agency shall be a nonpolitical, nonreligion, and nongovernmental organization dedicated to promote the welfare of blind children up to 16 years of age;
- b) The ABC shall be a funding agency and provide:
 - i) Equipment for blind children in existing and future educational institutions;
 - ii) Financial assistance for treatment and cure of children who possibly could have their sight restored;
 - iii) Assistance and funds for sponsorship of blind children within or outside of institutions including such programme as "family-to-family" sponsorship;
 - iv) Support to small rural centres for blind children where educational and working skills can be developed and imparted;
 - v) Support for training of teachers of blind children;
 - vi) Support to projects for collection of data and documentation relating to the situation and status of blind children in the country;
- c) The ABC shall organize seminars and workshops on training and rehabilitation services for blind children, especially those in rural areas, and take such other measures for projecting the needs of blind children. It may undertake projects for the welfare of blind children in cooperation with other national and international agencies on regional and global basis.
- d) Funds for programme as outlined above could be provided to governmental and nongovernmental agencies as well as needy individuals after due appraisal made by the agency.

Since its inception, ABC has taken up the following projects and a brief resume of its activities is given below:

- a) Restoration of Eyesight: A total of 560 blind children have been so

far operated on in different eye hospitals of the country for restoration of eyesight. All financial support in this regard including the cost of traveling and subsistence of their attendants have been borne by ABC.

b) Stipend for blind students: Every year ABC provides stipends to blind students who are prosecuting studies under the Integrated Education Programme of the Government, from Class I to class V, as day scholars. ABC provided monthly stipend @ Tk. 100/(US\$ 4/) to 62, 54 and 88 blind students in 1980, 1981 and 1982 respectively. Similarly, 83 blind students are being provided with stipends during 1983. Besides, ABC provides Braille Kits, Braille watches and Braille text books to the blind students of the country.

c) ABC Sponsored Hostels for Blind: It has been found almost impossible on the part of blind students to attend schools from their respective homes. It has prevented many bright students from continuing their studies. To mitigate their problems, ABC has already commissioned 5 hostels for blind students at Mymensingh, Jamalpur, Sirajganj, Comilla and Brahmanbaria under the integrated education programme of the Government, where blind students are receiving sponsorship from ABC; on an average they get financial assistance from ABC @ Tk. 300/(US\$ 14/) per month. Each hostel accommodates 10 to 12 students. In view of the tremendous need, two more hostels will be set up soon.

d) Rehabilitation of Rural Blind Children: It has been carefully observed that the scope for imparting vocational training to rural blind and their subsequent absorption in open employment is very limited. This project has been taken up to check the influx of rural blind to urban areas, at the same time creating avenues for making them self-reliant at their own home situation. With this end in view, a pilot project was undertaken in the district of Mymensingh, in 1980. So far, 85 blind children have been provided with heads of cattle, chicks, ducks and goats for their economic rehabilitation. Mention may be made that 74 of them are at the moment income generating and depositing their savings with respective Bank Accounts. The rest are expected to be income generating by the middle of the current year (1983). The largest of this project is to rehabilitate another 35 clients during the same year.

Being encouraged at the success of this project another similar project has been initiated from March this year in the district of Comilla and it has been planned to rehabilitate 20 blind clients of that area during 1983.

e) Sports & Cultural Meet: ABC organized a 2nd Annual Sports and Cultural Meet on 31st January 1982, which was participated in by 81 blind, of whom 61 were boys and 20 girls, from 13 Educational Institutions of the country. The next Annual Sports and Cultural Meet of ABC will take place towards the end of the current year where we expect more participation by blind boys and girls.

ABC COMPLEX: To sustain the present activities of ABC and also with a view of expanding its activities, ABC decided to set up a complex with joint collaboration of the Government of the People's Republic of Bangladesh. The main objectives of this Complex is to offer screening of eyesight of rural children of Bangladesh through Mobile Ophthalmic Unit and thereby educate people about eye health care for prevention of blindness and, secondly, to act as a Resource Centre for imparting training to professional and paraprofessional workers for the blind in the field of personal adjustment training, vocational counselling and parents counselling by qualified teaching staff in residential situation and, thirdly, to produce braille reading materials. The Centre shall have the capacity to accommodate 24 trainees at a time. The estimated cost of the project is Ta. 5 million, of which the Government of Bangladesh will contribute Ta. 174 million and ABC has to contribute Ta. 2.826 million. ABC has so far spent Ta. 0.848 million for purchase of one acre of land and its development out of ABC's own sources. The construction work has just started and it is expected that the construction work will be completed by December, 1983 and the Complex will be in operation from January,

1984. This comprehensive programme will be the first of its kind in this country.

The motto of ABC is "A Future for Every Blind Child Give sight back to those who can recover it and dignity to those who cannot" and seeks cooperation and assistance from national and international organizations for fulfillment of the objectives of ABC.

THE STATUS OF THE VISUALLY HANDICAPPED

INFANTS YOUNG CHILDREN (BIRTH TO SEVEN)

IN THE MIDDLE EAST REGION

Sheikh Abdullah M. Al-Ghanim
(Saudi Arabia)

Introduction:

The child is the nucleus of human society and the most reliable resource therein, to whom we feel more and more attached in so far as his need of us is ever increasing. In return, our sense of responsibility towards the child is rapidly growing, particularly in case of a handicapped child.

Modern trends are presently showing unquestionably proper considerations for childhood. Similarly axiomatic acknowledgements have in its entirety highlighted the interest in the today childhood for building up future generations. In this respect, we would like to emphasize the fact we should acknowledge that the child is entitled to care, welfare and protection as a human being notwithstanding the role he can play in his society as the future productive power.

Welfare of the childhood is not a new topic, but the aspect thereof newly dealt with nowadays is related to such categories of our children whom we should recognize as entitled to receive special attention, welfare and care; that is to say the visually handicapped children who necessitate to maintain social awareness and understanding allowing for the difficulties which may impede their existence and restrain their aptitudes for integration into everyday life. This category of people has its own status which dictate upon us to take specific and specialized actions for safeguarding, breeding and rehabilitating them. It is therefore incumbent upon us, if we are desirous to promote the available services in this field and to avail ourselves efficiently thereof, to recognize the requirements of the visually handicapped child and to comprehend the aspects of his handicap; henceforth we work out for the success of the services rendered to satisfy such requirements through collaboration among all efforts and scientific, technical and social potentialities needed. It seems that such collaboration cannot be established unless the bodies concerned with the breeding and education of the child, whether governmental, individual or domestic, shall maintain ceaseless and comprehensive specified collaboration, organization and planning.

The magnitude of the problem in the world - as you know - is seriously aggravating, especially among the children in the developing countries. One feels heartily distressed and disappointed to see such lamentable status of those children. The recent data report that among each fourteen blind children in the developing countries only one child and his family receive adequate care and necessary services. Nearly 250,000 children lose their eye sight every year in such countries due to the lack of proper nutrition, especially vitamin "A".

In the light of such findings and dimensions which highlight the collectivity and togetherness of human society stressing the rights of childhood at large with particular emphasis on the handicapped children, we look forward to the significant role about to be played in this respect through your humanitarian symposium.

Population Data and Magnitude of the Problem in the Region:

The population of all Middle East countries is estimated at 250 million persons, and the statistics currently available in this field indicate that about

7.5 million people in the Middle East region are totally blind, the majority of them are children, i.e. the blind people represent 3% (three per cent) of the total population. Additionally further millions are undergoing low or impaired vision whereas two thirds of them at least could have been prevented or cured, should sound methods of medical and hygienic care had been earlier applied. Nearly 150 million people are liable to be afflicted with eye diseases, especially trachoma in case proper preventive and curative measures are not immediately taken.

Due to the lack of accurate data and information available in this respect, it is greatly difficult to measure the magnitude of the problem of blindness in the Middle East region with all its aspects, especially in connection with the children. The scarcity of statistics, studies and specialized research, represent one of the major hardships and difficulties encountered in the Middle East region.

As regards the Kingdom of Saudi Arabia, no officially verified data has been as yet available about the magnitude of the blindness problem. However, in the light of some serious estimates and investigations on the basis of some surveying studies conducted on the local eye clinics and hospitals, the percentage of blindness in Saudi Arabia is roughly 2% of the total population. As the latest formal census indicates that the population in the Kingdom of Saudi Arabia is around (8) eight million people, the number of the blind people therein must be 160 thousand persons.

Major Causes of Eye Diseases in the Children Below Seven:

Trachoma is deemed one of the major causes of blindness among children in the region, as not less than 100 million cases are liable to be afflicted by various eye diseases, especially trachoma.

Conjunctivitis, Glaucoma (which may be congenital) as well as congenital cataract are of the other causes for blindness among newly-born babies.

There is another cause for visual handicap among children which is considered not less dangerous than other causes in area; it is the confusion of light refractions in the eye such as Myopia or Hyperopia that results in the squint disease of 3% between young children, sometimes Amblyopia cases also discovered.

In some countries such as Sudan and Yemen, Onchocerciasis is prevailing and forms another major cause for blindness. The rate of blindness in some parts of Sudan is estimated at 5.1% out of which 4.9% due to Onchocerciasis.

Naturally, there are other blinding causes in the Middle East Region, as it is the case in the remaining states of the world, such as German Measles that attack pregnant women, various types of accidents and other causes.

General Attitudes of the Family Towards Blindness:

In most Middle East countries, the family is characterized by binding relations and tenacity in spite of civilizational expanding waves and social and economical changes these countries are witnessing. Naturally, these are flowing out from the social structure of those societies and their adherence to the religious teachings that stress on social linkage and necessity of embodying ties of love and brotherhood between society members. For this reason, the family in this area still reserves many of the inherited original traditions and customs, strong ties and the moral educational values which all reflect the family complete interest in its members, particularly children, and encircle them with all protection and welfare measures. But in spite of all that, family view towards the child mostly differ according to his health, physical and mental condition. So, the family warmly receives the normal child with open arms, pleasures and welcome. On

the contrary, a handicapped child is viewed as if a disaster or catastrophe fell down on the family. Therefore, in most cases family attitudes towards blindness are negative and mixed with fears, anxiety and tension. This is a result of the parents' permanent anxious feeling about their handicapped child and his future. They feel also their inability and perplexity in meeting his needs, and in helping him grow within his potentialities. Parents, in general, exaggerate their concern with this child, excess compassion for him due to their fears and anxieties to save and protect him, which naturally will lead to set bounds on him instead of freeing him and accelerate his independence and self-reliance. This is in addition to his permanent feeling that he differs from others, subsequently feeling insecurity and a lack of tranquility.

Thus we can - in general - classify attitudes of the family in the area as follows:

- A group of people oversympathizes with the blind child. Another group has excess cruelty and violence in treating such a child, but considers him dependent on the family and the society. Their treatment denotes disgust and ashamedness from the child and his handicap. Keeps him away from visitors, rarely mentions him, and forces him to live in a secluded room wherein he is supplied with his food and drink.

The Regional Bureau had faced many cases of such type where it managed to resolve some of them, but it stood doubtful and helpless before most of those cases, could do nothing toward them. Meanwhile, the moderate group who is neither characterized with oversympathy nor with deadly cruelty represents only a small percentage among families of the blind children. We hope that attitudes of the family towards the blind shall - thanks to awareness - be improved whether in the Middle East or other developed countries that suffer from the same problem.

So the family in our region is still in need of profound knowledge, understanding and right awareness, not of the visually handicapping causes and their preventive measures only, but also in understanding requirements of the blind child and the best method to treat him. The family needs, also, guidance to help the child acquire physical and adaptive elaborated skills, in addition to social skills, enabling him to establish successful relations with other people in the future.

Of course, realizing all these hopes demand from parents more experience, training, understanding and patience while treating their visually handicapped child.

Thus, in our opinion, this subject should be given first priority, for I consider the family is the preliminary social establishment which provide the visually handicapped child with indispensable, basic and essential services. In this way, the family is a fundamental element for the success of any service of this type.

Effort and Activities of Regional Bureau in the Field of Prevention of Blindness and Care for the Blind Children:

The Regional Bureau has, since its establishment, exerted all efforts to prevent blindness and eliminate its causes in the Middle East region, thus heading assiduously straight to terminate the horrible prevalence of blinding diseases, with particular emphasis on the remote areas which more urgently need adequate hygienic services.

Loss of eyesight which is mainly due to communicable eye diseases, could be prevented or cured by setting up programs to ensure early detection and prompt treatment of eye diseases, by providing simplified means of eye care to be availa-

to everybody, by launching further awareness campaigns on how to keep eyesight safe through earlier medical treatment, good nutrition and adoption of sound hygienic habits. So efforts, activities and achievements of this Bureau are outlined in the following points:

1. To make contacts and consultations with national and international specialized organizations and agencies; the most prominent of which are the World Health Organization (WHO) and the International Agency for the Prevention of Blindness (I.A.P.B.), and spare no effort in recruiting an elite of regional and international experts and specialists to conduct the necessary research works and studies aimed at obtaining the most accurate data and best results in this field. This step has yielded fruitful results in the field of prevention of blindness and the control of blinding eye diseases and eye disorders among children.
2. To collaborate from time to time with some countries of the region in conducting comprehensive surveys of eye diseases in hospitals and out-patient clinics with a view to track down prevalent endemic diseases and detect the place of the prevalence. The latest that was carried out was the survey conducted by a group of ophthalmologists from Saudi Arabia Universities on the students Al-Noor Institute for the Blind in Bahrain and which yielded fruitful results with regards to identification of blindness and low vision causes as well as such eye diseases most prevalent among the students.
3. The setting up of the Permanent Advisory Eye-Hygiene Committee of Gulf Arab States; a committee whose membership consists of each of the Kingdom of Saudi Arabia, the State of Kuwait, the State of Bahrain, the State of United Arab Emirates, the Sultanate of Oman, and Iraq in addition to a delegate from the Regional Bureau of the Middle East Committee for the Affairs of the Blind. This committee was assigned the task of supervising the programs of blindness prevention and the study of the problem concerned with eye diseases in the region and finding the most optimal solutions for it.
4. The collaboration and coordination with Maternal and Child health centers in the region countries. These centers undertake the medical examination of pregnant mothers and children with special attention to eye inflammations and disorders.
5. Urging the states of the region to pay more attention for the periodic examination of children's eyes in nurseries and kindergartens so as to have an early diagnosis of their diseases and offer them early the most adequate treatments.
6. To issue and circulate publications, booklets, leaflets and posters of informative and guidance in nature regarding eye protection and practice of good hygienic habits.
7. The cooperation with responsible authorities of the region states in adopting comprehensive awareness programs in the field of eye sight protection and eye diseases prevention.

The Regional Bureau has contributed in planning the general framework of such programs being based on the following domains of activity:

- The implementation of sound hygienic habits in connection with eye health.
- Through attention to mother and child nutrition.
- To arrange for early and systematic medical examination of new-born children in order to detect the probable existence of any eye disease.
- To emphasize the importance of early diagnosis and treatment of eye diseases as well as the adoption of safety rules whether indoors or outdoors.
- To denounce what may be still persistent in the mind of citizens as badly based opinions and superstitious interpretations of certain syndromes and diseases, characteristic of the eye.

- To emphasize eye-health protection of the fetus during prenatal, postnatal and through various developmental stages.
 - To emphasize the importance of immunization against diseases and to provide the children with the necessary types of vaccinations throughout various stages of age.
8. To launch awareness campaigns in the field of prevention of blindness by issuing informative publications, booklets and writing articles in newspapers and magazines as well as by preparing Radio and T.V. programs at various occasions, the most important of which were the International Year of the Child, 1979, and the International Year of the Disabled, 1981.
 9. To organize, from time to time, scientific and medical symposia in the field of prevention of blindness among children. The most prominent of these was the pediatric symposium about handicapped children, held during March, 1978, in three principal cities of the Kingdom of Saudi Arabia, in cooperation and coordination with the ministries of Health, of Education, of Labor and Social Affairs, of High Education and the International Organization of Cerebral Palsy.
This symposium included the discussion of numerous subjects and studies in the field of pediatrics of handicapped children such as Prenatal "Child Care, Early Treatment of Certain Handicaps, Evolutive Neural Examination of New-born Children,...etc."
- Also contributed to this symposium an elite of famous physicians and international specialists in Pediatrics, Obstetrics and Gynecology. The symposium yielded good results as it succeeded to put in relief the problem of handicapped children in addition to the importance of early Handicap Treatment and Prevention.
10. The Regional Bureau has been particularly concerned with the subject of Low Vision Children in view of its greatest importance in the field of the prevention of blindness. It has also drawn the attention of the Middle East States to emphasizing and allowing for the subject in all health programs by establishing specialized clinics for the low vision and partially sighted people, especially when this Bureau had left the increasing need for this service and the insurance of its availability in each state with view to render proper services to those suffering low vision and partial sight, particularly to those who are deprived of such services for the protecting of their eye sight or their low vision not to deteriorate into total blindness.

These are the most important activities and accomplishments we realized in the field of prevention of blindness in the Middle East Region. There are also many activities and services this Bureau has rendered to the blind children at large in the field of welfare rehabilitation and education through the relative institutes and institutions affiliated and located in some states of the Region, the most important of which is: Al-Noor Institute in Bahrain which is financed and supervised by this Bureau. This Institute was opened early in 1974. At present, it consists of two main sections; Academic (Elementary and Preparatory) and Vocational (Theoretical and Practical) as well as the boarding sections for males and females with a kindergarten. It now accommodates more than 150 male and female students from various states of the Gulf region; twenty of them are below 5 years.

In parallel with these important activities and achievements performed in this field, other activities are being practiced by our Bureau for the Blind adults through supervision of the blind students in schools and universities and provision for their needs of books and equipment required. We have managed integrating blind students with their sighted counterparts in the secondary stage of education. I would like to assure you that we are still at the beginning of the road where lots of efforts and continuous works await us. However, we feel from

our previous experience in the field of social, promotion, protection, and general welfare, with all the aspects of care of the visually handicapped people, including the field of blindness, that all the efforts and services we offer will remain limited as to their effects unless the organizations concerned in this field join in efficient cooperation, consolidated efforts, exchange of information and experiences among all agencies, organizations and bodies working this field.

Finally, this leading International Symposium is considered a good initiative, which is hoped to result in further acquaintance with activities of all people and organizations working in the service of the visually impaired children for fostering friendly relationships among them. It is also deemed a substantial and necessary step and an explicit invitation for further coordinated work towards the creation of the proper atmosphere for developing social, educational and medical services required in this field.

Let me thank you all for the opportunity you have given me to meet with you and wish your humanitarian symposium every success.

REGIONAL REPORT: U.S.A. AND CANADA

Susan Jay Spungin, Ed.D.
(U.S.A.)

It has been two years since I have been asked to give a report on Pre-school Services in North America and I am happy to say, since that time, two very important individuals have entered the field of early childhood education for the visually handicapped who have made my reporting job much easier. Namely, Dr. Kay Ferrell, National Consultant on Early Childhood with the American Foundation for the Blind in New York and Cheryl Richesin, National Consultant in Childrens Work and Rehabilitation teaching with the Canadian National Institute for the Blind in Toronto. Consequently, much of what follows is a direct result of the communications I have with these two professionals.

The United States

At the present time there are approximately 9,400 visually impaired children under the age of 6 in the United States. Of this number 6,450 are under the age of 4. It is projected by the 1977 United States Bureau of Census that between 1979-1990 there will be a 25% increase in the population of children under the age of 5 in the United States. To extrapolate, therefore, one can anticipate an increase of the visually impaired population of children under 5 to reach about 12,000 by 1990.

At present, Dr. Ferrell is updating a 1978 preschool survey by Spungin and Felix. With 40 out of 50 states responding, 412 preschool programs have been identified. That is 180 programs added since the '78 survey or an increase of 78%. Of the 412 programs, 322 are run by local educational agencies with 96% being generic or non categorical. Only 13 of the 322 programs indicated that they only serve visually handicapped children. Ninety nine percent of the additional programs identified since the '78 survey are at the local educational level.

Further breakdown of 412 programs:

13 private, VH only; 40 state departments of education, or state agencies, including rehabilitation; 23 residential school services; 14 other (United Cerebral Palsy, Easter Seals, etc.)

Some of the implications are:

Most programs added since 1978 are run by Local Education Agencies (LEAs). More children are being served in generic programs by local public schools. Only 14% of all services are geared specifically to VH (this may be an underestimate, since right now there is no clear indication of how many LEA programs have VH teachers involved).

Increasing number of rehabilitation agencies are becoming involved with pre-school children.

Eligibility requirements by statute or state plan varies from state to state but are summarized as follows:

Mandatory Services, Birth + School-age = 12 (23.5%): Delaware, Hawaii, Illinois, Iowa, Maryland, Michigan, Nebraska, New Jersey, South Dakota, Texas, Vermont, Virginia

Mandatory Services, Age 3 + School-age = 10 (19.6%): Alaska, California, Indiana, Louisiana, Massachusetts, Montana, New Hampshire, Rhode Island, Wisconsin, District of Columbia

Of the above, those states which permit services for Birth - 3 year olds = 5 (09.8% of total): California, Louisiana, Montana, New Hampshire, Wisconsin
Mandatory School-age, but Permissive Birth - 5 years = 13 (25.5%): Arkansas, Connecticut, Florida, Georgia, Idaho, Kentucky, Minnesota, Mississippi, Missouri, Nevada, North Carolina, Ohio, Washington
Mandatory School-age, but Permissive 3 - 5 years = 6 (11.8%): Alabama, Colorado, Kansas, North Dakota, Oregon, West Virginia
Mandatory School-age Only = 10 (19.6%): Arizona, Maine, New Mexico, New York, Oklahoma, Pennsylvania, South Carolina, Tennessee, Utah, Wyoming

Implications:

Where services are not mandatory, residential schools and state agencies, including rehabilitation, appear to be taking up the slack.
 Services for VH are sometimes mandated in some states which do not mandate services for other handicapping conditions.
 Expect LEAs to become more and more involved in early childhood education.
 More states cover 3 - 5 year olds (in some fashion) than 0 - 3 year olds.

There will continue to be a critical need for early identification and services, particularly as birth rates increase and mothers' ages increase due to emphasis in the U.S.A. on the working woman.

The most common eye conditions among this preschool population remain to be:

1) Prenatal cataracts, 2) Optic Nerve Atrophy, 3) RLF.

The RLF youngster, however, has presented us with some differences from those of the past born in the 1940's.

Some RLF Statistics

In the 1970's-1980s, there has been little increase in advanced cicatricial RLF (severe visual handicap), but a huge increase in active proliferative RLF (early stages, often resolves spontaneously).

10% of premature infants in oxygen will develop active proliferative RLF, but only 1/3 of these will develop cicatricial RLF. Only 250 of these will become totally blind.

RLF cannot be eliminated if physicians are going to address respiratory distress syndrome and cerebral palsy. (Which is worse? Visual impairment of brain damage?)

Might expect RLF to occur more often as doctors save smaller and smaller babies.

1950: 8% of premies under g. survived

1980: 35 - 50% of premies under 1000 g. survived

85 - 90% of RLF regresses spontaneously.

Risk factors for RLF:

low birth weight, length of time in oxygen, oxygen concentration, gestational age, apnea episodes, resuscitation, septicemia, degree of illness, blood transfusions, intraventricular hemorrhage, mechanical ventilation.

New cases of RLF occurring at a rate of about 2100 per year. 550 become visually handicapped; 200 - 250 become totally blind.

(Notes from lecture by Dr. John W. Payne, Asst. Prof. of Ophthalmology, Johns Hopkins University. At seminar presented at Maryland School for the Blind, October, 1982.)

Canada

As of June 1982 Cheryl Richesin has been appointed by The Canadian National Institute for the Blind (CNIB) to help coordinate preschool services for visually handicapped throughout Canada. I believe one of CNIB's Children's worker in Preschool is here with us from Alberta, Ms. Winnie Tse. I suspect she can offer much more detailed information than I can at this time.

Canada is divided into 12 provinces with the CNIB covering the entire country with 8 divisional offices. The national office in Toronto offers consulting services in British Columbia, Alberta, Manitoba, Saskatchewan, Ontario, Newfoundland and, of course, Toronto. At the present time CNIB has some 13 children workers and/or consultants responsible for the visually handicapped preschool population.

There are 471 legally blind age 0-5 children registered with CNIB as of 1982. In addition they serve other children who have visual difficulties but can see better than 20/200. They too notice an increase in RLF similarly to the U.S.A.

There are really two major residential schools for the blind in Ontario and Halifax and the percentage of children integrated varies from province to province.

The child care workers had their first meeting in March of 1983 and came from varied educational backgrounds in psychology, sociology, O.T., early childhood and counseling. At the present time there are no universities training programs in Canada for preschool workers for visually handicapped but rather heavy reliance on experience and inservice training. Their greatest problem is the isolation of professionals and the need to meet more often and share information.

Conclusion

Although the U.S. has a training program for preschool teachers of visually handicapped at Michigan State University in East Lansing, I believe we too feel isolated and in need of information. Imagine how the parents of these children must feel! It is for this reason I would like to conclude with a brief discussion of AFB's federally funded project on material development.

MEETING THE TRAINING NEEDS OF PARENTS OF VISUALLY HANDICAPPED/MULTIHANDICAPPED YOUNG CHILDREN

A three year project funded by the U.S. Department of Education and conducted by the American Foundation for the Blind.

The goal of the project is the development of training materials for parents of blind and visually impaired infants and young children. Its first priority is to meet the needs of those parents who do not have access to early intervention services. Consequently, the core of the materials is being designed for use by parents without professional assistance or with a correspondent teacher at the Foundation as their sole contact. In addition, slide and tape presentations are being developed to match this basic material. These are more likely to be used by professionals working with parents, either in the home or in a group setting. An Instructor's Manual for teachers using the entire package will be developed in the third year of the project.

The instructional materials have been grouped into six modules each dealing with a cluster of related parent competencies. These competencies were selected on the basis of a survey of parents, teachers and blind adults which constituted the initial, research, year of the project.

Three of the modules are to be field tested in the Spring of 1983. The

remaining three modules will be field tested during the last year of the project. The themes of the six modules are:

- | | | |
|------------|--|---|
| Module I | Perspectives-educational opportunities and long term prospect for blind and visually impaired persons. | |
| Module II | Reach Out and Teach - an introduction to the parent's role as teacher. | |
| Module III | Motor Development | |
| Module IV | Sensory/Cognitive Development | enhancing the child's development in specific areas |
| Module V | Communication/Self-help | |
| Module VI | Self-worth/Mental Health - Coping with emotional problems, family relationships, behavior problems and obtaining help when needed. | |

These materials will be field tested by providing them to individual parents through the correspondent teacher at the Foundation and through workshops, for parents only, during the current year and for parents and teachers in the final year.

In addition, an extensive bibliography of existing materials was developed as part of the research phase of the project. It is now available in its global form. It will be used eventually to provide selected references related to each module for both parents and professionals.

I have brought with me today some 50 copies of materials listing pre-school publications for parents, curriculum materials, deaf/blind materials and toys with information on availability, cost and comments where appropriate. I hope these will be helpful and if there is not enough to go around, please leave me your name and address and I will send you a copy.

Thank you.

OCEANIA REPORT

Pat Jarrett
(New Zealand)

Demography:

New Zealand has a population of 3.1 million people and more than half of these live in the northern half of the North Island. Auckland, with a population of 770,000, is the largest city and it is here that the Royal New Zealand Foundation for the Blind is based, providing services to members throughout the country. Geographical features and the decrease in population from north to south makes it difficult to provide adequate services for young visually handicapped children. There are 6000 people enrolled with the Foundation for the Blind, who make up 0.2% of New Zealand's population. Of these, 180 are in the 0-8 age group. In this age group, 56% have partial sight, 32% are severely multi-handicapped and 12% are totally blind, without other known handicaps. Visual handicap is not a notifiable disorder and enrolment with the Foundation for the Blind is voluntary. The statistics in this report are based on the 180 children enrolled.

There are 300,000 Maoris and 91,000 Pacific Island Polynesians living in New Zealand. 44% of the children visited in the Auckland area are of Maori or Island descent.

Parents of visually handicapped children can apply for a handicapped child allowance of \$12.50 a week.

Major Causes of Eye Disease and Blindness:

The six major causes of severe visual handicap in children under the age of eight, are:

- Optic atrophy	19.4%
- Congenital cataracts	14.4%
- Albinism	13.3%
- Cortical blindness	12.7%
- Retrolental fibroplasia	8.9%
- Nystagmus	7.7%

Efforts for Prevention of Blindness:

Genetic counselling is available when there is a known family history or after a child is born with a malformation or eye condition.

Since 1979, rubella immunisation has been offered to 11 year old girls and a 98% protection rate has been achieved. Low percentages are recorded for the testing of rubella immunity in women of child bearing age, who may have missed earlier immunisation programmes. The 1982 Child Health report, (pg. 206), states that "To prevent a repeat of the 1980 scale epidemic of congenital rubella in the future, rubella immunity screening and immunisation if necessary, will have to be adopted before pregnancy, by all women entering their child-bearing years".

With more low birth-weight babies surviving, retrolental fibroplasia is showing a marked increase. A study of babies with a birth-weight of less than 1500gm, is being undertaken in Auckland at the present time.

Publicity for the prevention of accidents, emphasises safety in the home and in motor vehicles, toy safety and safety with fireworks.

About half the children under the age of four, in New Zealand, are vision-tested by Plunket Nurses and Public Health Nurses. This is mainly for the detection of amblyopia. Almost all children have their vision checked at school, at ages 5 and 11.

General Attitudes to Blindness:

Reactions of the family to the knowledge that their child is blind or severely visually handicapped, are many and varied. Inevitably, there is shock and disappointment and acceptance of the handicap can take years. Sometimes it is never achieved. This is apparent even in families where the condition is hereditary, although these families have the benefit of previous experience and for some of them, blindness is normal.

From observation, it would seem that acceptance comes more readily when there is early referral to a supportive agency, where early intervention is carried out and where there is on-going support for family and child.

It would appear that the attitude of some of the polynesian races is that everything must be done for the handicapped child. This leads to difficulties when working with these families, when together with language and communication problems, there is a cultural attitude against the development of independence.

Description of Programmes:

Auckland is the only centre in New Zealand where numbers warrant a special pre-school for visually handicapped. Most partially sighted and some blind children attend normal preschools. Homai College, the educational facility, funded by the Department of Education and administered by the Foundation for the Blind, has a developmental centre for young multi-handicapped blind and to prepare blind children for entry into normal pre-schools where this is advisable. The centre operates five days a week, with children attending full, or part-time. Residential care and transport is available, if necessary. There are currently seven children on the pre-school roll and ten in the developmental centre. Individual programmes are designed for each child, based on the Oregon Project and the Callier Asuzu Scales. The programme for the multi-handicapped children is predominantly language development, with signing used as an aid to communication.

The staffing at the pre-school includes a full-time kindergarten teacher, with part-time speech therapist, physiotherapist, teacher aid and house staff. Developmental Centre staffing includes a teacher, speech therapist and house staff working full-time, with part-time teacher aid, physiotherapist and house staff. Consultant services are provided by an ophthalmologist, psychologist and pediatrician.

In addition to this, playgroups for mothers with babies operate until the child is ready to separate from mother, usually at about three years of age.

Parents outside the Auckland area are invited to bring their child to Homai College as required, for a week of 'Parent Training'. During this time, the resources of the College are made available to provide an intensive programme and suggestions are made to assist the professionals working with the family in the home area. Parent seminars are held on an irregular basis. The next one in June, is a workshop to assist parents of pre-school blind with the making of tactile books.

Outside Auckland, services for visually handicapped children are provided by Child Health Clinics, Crippled Children's Society and Intellectually Handicapped Children's Pre-Schools and early intervention programmes organised by the local psychological service. Visiting therapy services are available in most parts of New Zealand and to a lesser extent, speech therapy. There are a number of Toy Libraries throughout the country and the Correspondence School has an excellent section providing educational material for children with special needs. Pre-school children in Wellington, Christchurch and Dunedin are visited from the Visual Resource Centres in those areas.

The Foundation for the Blind employs one pre-school services officer to visit all registered children 0-8 in their homes and pre-schools and to liaise with professionals in the area throughout New Zealand. The 1982 Child Health Report, (pg. 92), states that the provision of appropriate education programmes for blind pre-schoolers remains unsatisfactory in many parts of New Zealand.

With the low incidence of visual handicap in the total population and lower populations outside the Auckland area, it is inevitable that young visually handicapped children will continue to receive services from agencies geared to dealing with a variety of handicaps. These agencies and the families themselves, need more support from the Foundation for the Blind than is currently being received in the form of advisory services, resource material and counselling.

Those children in the Auckland area, who are attending the Homai College Developmental Centre, are receiving good attention. Earlier and better referral has meant that there are a number of young blind children in the Auckland area who are not receiving adequate early intervention. Pre-schools with blind and visually handicapped children on their rolls, are receiving little support. Most agencies catering for the handicapped in Auckland are over-loaded. More trained workers are needed to work with pre-school visually handicapped, both in Auckland and in other parts of the country. There is no training programme available for teachers of visually handicapped children. With the high proportion of polynesian families in the Auckland area, personnel with a knowledge of their language and customs would be an advantage.

The Report of the Committee on Child Health (Child Health Report, pg. 322) suggests that the current priorities for improvement of services for all handicapped children in New Zealand are:

- co-ordination of services
- family support services
- assessment services
- government aid for voluntary organisations
- special treatment facilities
- special educational facilities
- community facilities
- publicity

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OCEANIA REPORT

Mr. T. L. Rogerson
(New Zealand)

In Oceania, the extended family is the most usual form of social organization.

The region extends from Papua New Guinea, Australia in the West of the Pacific, to Pitcairn, Tuamotu, Marquesas in the East and to Washington, Fanning and Kiribati (Gilbert Islands) in the North, New Zealand and the Campbell Islands in the South.

Note that the International Council for the Education of the Visually Handicapped (I.C.E.V.H.) has made contact with the following countries: Australia, New Zealand, Papua New Guinea, Solomon Islands, New Hebrides, New Caledonia, Marshall Islands, Phoenix Islands, Fiji, Tonga, Cook Islands, Samoan Islands, Tokelau Group, Line Islands, Kiribati (Gilbert Islands), and Marianna Islands.

They were invited to contact this organisation if there was any way in which we could assist the visually handicapped in their country.

Because of the Social Structure, it was I.C.E.V.H.'s belief that it would be better not to single out any one area of the cultural chain for intervention, without local consultation and careful consideration of the cultural 'chain reaction', hence the difficulty we find in completing the questionnaire circulated by Helen Keller International dated 11 November 1982.

I.C.E.V.H. has had replies from Tonga, Papua New Guinea, Tuvalu, the Solomon Islands Red Cross, Fiji and, of course, New Zealand and Australia (who will be represented at the Conference and submitting their own reports - Pat Jarrett and Mrs. Jan Stanford).

We will continue, however, to encourage and support the people of the Oceania region in the following practical ways:

a) Collect information and statistics from informants who travel within Oceania/Pacific region, viz; Dr. S. Tompkin, Dr. Hazra Ishmail, Mr. C. Limpus and Ms. Faith J. Watts; to work closely with: Foresight (overseas Aid Committee of ANCB); HKI; WCWB; IFB; and CBM.

b) A one day conference in Adelaide, Australia in January 1984, at the Australian and New Zealand Association for the Education of the Visually Handicapped Conference.

c) To maintain close links with I.C.E.V.H., Asian region. Special note is made of the work of Dr. Hussain Ardisadmita, Indonesia and Professor Juliet Gregoria, Philippines, (I.C.E.V.H. Educator, June 1982 refers): No doubt, these papers will be further discussed in Aruba.

I.C.E.V.H. membership at present stands at 81. We will be endeavouring to increase this membership and be setting up a loan making rural/urban type bank fund, from which Oceania located groups assisting visually handicapped people of all ages, including pre-school, may borrow funds to enable them to become more independent in terms of that culture's norms and mores.

As many students in the Pacific area finish school at an early age, it is difficult to know whether or not partial sight required for school work is rare, prevalent or very common. This is a field that we will be further surveying with Dr. Tompkin in the Tokelau Islands.

Although I realise that this paper will not be read at the Conference, I would very much appreciate its being included in the proceedings, as a summary of the contact people, hopes, aims and aspirations of I.C.E.V.H., Oceania. Any suggestions, ideas, criticisms or brick-bats may be sent to me, Mr. T.L. Rogerson, President of I.C.E.V.H., Oceania, C/- Homai College, PO Box 67, Manurewa, New Zealand.

Kāpai te korero.
Kia Ora!

(Bibliography attached to previous report)

THE VISUALLY IMPAIRED CHILD IN LATIN AMERICA:

ALTERNATIVE PROGRAMS

Susana E. Crespo
(Argentina)

Latin America covers an area of over 20,000,000 square kilometers, stretching from Mexico, which is part of North America, to the Southern tip of the republic of Argentina. It's inhabitants, a total of 304,270,000, according to the census of 1980, are distributed among seventeen continental countries and three Spanish speaking islands located in the Caribbean region. Indians and people of mixed blood are predominant in many countries; in others, the number of blacks is high, while in the southern half of the continent the majority of the population is white, of European origin.

The disparity in races brings along with it a disparity in cultures, and with these, different socio-economic levels. The values, the hopes and the expectations of those of mixed blood or the Indian are not the same as that of the members of the white race; their philosophy of life is not guided by the same parameters. The large extension of the territory, the diversity of Indian languages, mixed with Spanish and Portuguese, and the problem of communication due to the huge distances have affected the development of vast areas of the continent where civilization has virtually not yet reached. Therefore, we have large areas that are totally isolated from the cities and centers of progress. When, in addition to the geographic and human characteristics we add the high level of illiteracy, the lack of real economic resources, scientifically and technically trained professionals and a defined educational policy appropriate for the region which meets the needs, capabilities, and expectations of its inhabitants, we can, to some degree, understand the problems and limitations still facing the education of visually impaired children today in Latin America.

INCIDENCE OF THE PROBLEM:

One of the realities in the entire region of Latin America is the lack of definite facts that can reveal the extent of visual impairment among the population. The overall percentages estimated by the Pan American Health Organization are only estimates because there are many factors which make provided data unreliable; for example: discrepancies in the definition of visual impairment, different criteria in the classifications, socio-political reasons resulting in concealment of facts, lack of interest or motivation to study in depth the extent of the problem.

The 1980 "Report on International Rehabilitation from UNICEF" indicates that the occurrence and the severe effects of disability, impairment and handicaps (and this includes all types) is greater in countries in early stages of socio-economic development than in more advanced countries. Later on the report states, that "this is a result of factors that must be recognized and taken into consideration when the plans for supporting programs on prevention and rehabilitation of disability are developed for those regions".

The report lists some of the important factors as:

- a- The high number of poor families burdened with taxes
- b- Towns with a high degree of illiteracy and poor understanding of the basic means of health, education and welfare.
- c- Lack of knowledge at all levels - from the citizens of the villages up to the people in high authority - regarding accurate information about the disability, its causes, prevention and treatment.

- d- Barriers such as lack of funds, geographical distances and social barriers that deprive many children from benefiting from existing services.
- e- Lack of resources available for providing services that are highly specialized to benefit only a small number of children with impairments.
- f- Lack of, or weakness in, the structure of services related to health, education, welfare and vocational education.

Many of these factors highlighted in the report are overlooked by us because it is not within our power to find the solution to the economic situation of a large number of the population, to the high level of illiteracy, or to the lack of knowledge about elementary measures of health, education and welfare. Neither is it up to us to deal with financial resources or geographical and social barriers. I believe we could try to reduce some of the deficiencies, rechannel programs, suggest measures that could help to minimize the present obstacles and help find a solution to the situation presented to us in an objective manner.

Some of the issues mentioned could well be considered today. It may be interesting to try to:

1. Mobilize some of the community services operating on behalf of the general public (schools, hospitals, churches, community, and volunteer centers, neighborhood centers) in order to undertake the task of training and basic education for children with visual impairments living in areas where specialized programs do not exist.
2. Provide more assistance and support to the families of the children with visual impairments so that they can learn to: (1) accept him as he is (2) give him the attention required by his impairment with the means at their disposal (3) facilitate a form of adequate treatment in the home or in the closest area, thus avoiding the uprooting and the separation along with the negative psychological and affective consequences that such a situation creates.
3. To restate the problem in such a way that we can eliminate, according to the circumstances, highly qualified personnel, and replace them with suitable, experienced and dedicated personnel capable of serving.
4. Emphasize the need for coordination of health, educational and social action services in order to avoid the loss of efforts, the duplication of actions and the weakening of services.
5. Promote a broad and permanent massive campaign of education propaganda that would reach the most isolated places, providing graphic material written in language easy to understand, simple, attractive, and which would indicate the WHAT, HOW, and WHAT FOR so that inhabitants in rural areas, small villages, or big cities, including those governing, can be informed about the preventive, educational and welfare measures available for those suffering a disability.

PRESENT SITUATION

The latest and most current reports received describing the status of the visually impaired child under age seven in Latin America reveals that:

1. In the majority of educational centers there are programs at the kindergarten level where children more than five years of age and older are accepted.
2. There are programs for stimulation and early intervention for children under five, but these are very few, and consist in many cases of just sporadic, if not accidental contact with the baby and the family, without any prior planning, and without implanting reachable goals.
3. Services are not foreseen for children with visual impairments who have additional impairments (deafness, retardation, cerebral injuries, psychotic etc.) These often attend schools for the blind where they simply remain due to a lack of organized programs that could meet their multiple needs.

4. Another important fact that comes to light from the information gathered relates to the professional level of those responsible for the educational programs. Very few institutions have teaching and technical staff with the proper certification. In the best of the cases, teachers are trained on the job, or are graduates of professions not related to education. It should also be pointed out that there is a great flux of teaching personnel which interferes with the uniformity and continuity of the task, the gaining of experience and perfecting of skills. This problem is due mostly to the low salaries received by a teacher as compared with what he would get in other jobs requiring less effort and offering better possibilities for advancement.

From this limited and concise description we can extract two fundamental facts:

- a. The educational services to children under seven years of age do not meet the minimal needs of the visually impaired children in the region.
- b. There are not qualified teachers nor professionally skilled technicians in sufficient numbers to attend to and develop total programs which address the biopsychosocial aspects of the individual's education.

These two general conclusions (there may be more that can be made but time doesn't allow going into any deeper analysis) make us ask these questions:

WHAT can we do so that more visually impaired children are helped?

HOW do we do it?

WHERE do we do it?

WHO should do it?

The education of the visually impaired child must start as early as possible - as soon as the problem is identified by physicians and the family of the child. The reasons that justify the existence of early programs are well known and I do not want to be redundant by repeating them for there may be other papers describing these programs; papers that, without doubt, will contribute to clarify concepts, define positions, analyze methodology of action and pointing out the important work that an interdisciplinary team can accomplish within the entire structure of these programs.

I prefer instead to concentrate on an idea, a proposal or suggestion that could bring closer in some way the solution to the initial education of babies and children with visual impairments living in rural zones isolated from more populated areas. I am talking about formulating alternative programs whenever the conditions are nonexistent, the optimum possibilities or even minimal in order to provide services to meet the needs of all children.

Before I go on, please allow me to take a moment to offer a personal commentary. With it, I only intend to show the changes, the stages that I have been through during my 38 years in this passionate and challenging task. Maybe my experience can help others who may be just beginning.

In the beginning, my work was purely intuitive, improvised. I knew that something had to be done for the blind in my city but I had no idea of "how to" and I knew little of "for what purpose". There was no one who could teach me, no one whose work I could copy, no place to read about methods, materials, or past experiences. I worked as if blindfolded, which taught me much through trial and error.

Later on when I was able to go abroad to study, I faced the real educational possibilities for the blind, what others were doing in other places, the results obtained, the equipment, and materials that were utilized for realizing this teaching. I then fell into a stage of high sophistication; of perfection. Everything around me would have to be as it is in the United States of America or Europe. If they can do it, why can't we? This led me to become careless, to ignore and to devalue what we had, by trying to translate the experiences and possibilities of highly developed countries to countries that were still developing,

where not only blind people were deprived but so were children with normal vision to whom the fundamental right to an education was being denied. In this stage I was neglecting the cultural, economic and social differences; I was only interested in doing what others were doing, attaining it at times with great sacrifice, wearing myself out, and with struggles that were not always satisfying. The results were not always what I expected, as I began to observe that at the end of the educational process, even when in many cases everything was achieved after using the most sophisticated resources, the end result was not what we desired. The blind client was not able to adapt to the city, he was a stranger there, he lacked the affective support of his family and his environment, he was not happy in a society where he belonged only because of his disability; in a society which he had not chosen and in which he was placed due to his need.

For some years now I have assumed a third view which is a summary of my two previous ones. Intuition - but not improvisation; professionalism but not sophistication; perfection - but adequacy. I remain convinced that the blind individual, whatever his condition, his origin, or his capacity, maybe needs to be offered the opportunities to realize himself as a man first, and then as a blind man. I am also convinced that he can only reach this within his social and familiar circle, without uprooting, without frustrations. It is a mistake to believe that just because an individual is blind he must receive a superior education, different from that of his brothers and relatives in the environment in which they live. If we do this, we are contributing to making an individual different, not because of his impairment, but because of schooling which has been given him by specialists.

We must educate within the environment where each individual lives, with the possibilities offered by that environment, with the difficulties that the inhabitants of that environment have to face, with the limitations imposed by geographical, human, and economical barriers. Everyone must be what he should be and blindness or a visual impairment is not a reason to distort or change this principle.

Coming back to "WHAT to do", I believe that the first thing to know is where are the children (name, address, conditions) and then to search for new, better and more effective ways to systemize their needs and adapt services to these needs.

Thus, if the baby lives with his family in a city where professionally qualified educational programs exist that are well structured with resources and real means to implement them, the child will no doubt benefit from the education provided by that program. If, on the contrary, the child lives in a rural zone, far removed from the city, neither he nor his family should be deprived from proper orientation or guidance; orientation that may not be as perfect, complete, or carried out as well, but that can represent the beginning of an educational and formative process. The important fact here is that the child is receiving something; that his basic needs are met, that his family and the community in which he lives and in which he will develop gets to know him, to accept him, to help him to plan his life according to what he is, what he and others expect, and not what the specialists believe that he should be because of his impairment of vision.

HOW do we attain this? Creating educational systems and alternatives, implementing simple techniques, creating basic elementary programs that can be put into practice by educators at the elementary level; by relatives of the children, by social workers, secondary school students, volunteers, etc.

WHERE do we do it? Bourgeault says, referring to the place where education should be imparted: "that we cannot indicate if in the residential school, public school or in the home, but that the objective that we must consider is that of implementing a system that makes education totally flexible, optimally effective and entirely individualized in such manner that it can serve EVERY visually

impaired child instead of the few that it presently serves." Interpreting Bourgeault I dare say: flexible, so that it can be adapted to the circumstances in which education must be imparted, effective, so that it can adapt to the needs of specific situations, individualized because not all children learn in the same manner, in the same amount of time and in the same environment. Each country, city or village has to identify their needs, characteristics and the potential of their population and act accordingly, adapting services, systematizing mechanisms that better lead to reach their proposed objectives.

Maybe the environment in which the child was born and is developing is poor, lacking in many aspects, but from an affective standpoint, it is his, it is to what he belongs to and what belongs to him. What do we gain by moving him away from the affection of those around him in order to create for him expectations that later can be difficult to satisfy? What we get is a group of youth and adults wandering through the streets of the big city, selling trinkets whenever they are not begging. In this environment they are strangers, they see no way to grow, they are ignorant of their potential, what they can do, what they are prepared for. The subject is ignorant of what his surroundings have to offer him, of the work of his parents, and what he can do for himself and for others. Even more: in the city he learned to cross the street with traffic lights, but in his village he is not able to jump across a ditch or a puddle because that reality did not exist in the environment where he was educated; he was taught to make crafts with fibers that aren't produced in his village, or to light a stove with elements that have not reached his region yet.

We now come to, "WHO". A teacher is not just an individual with such a title. It is one who serves, who puts effort, interest, good will, dedication, love, and trust in his mission. Because of this, if there are no professionals specialized in stimulating a baby in his early stages or to start the basic education of the visually impaired infant living in a rural area, there will always be a mother, a teacher, a nurse, a church member, or a volunteer willing to learn the basic principles that will allow him to orient the family and the child during the first steps of his education without creating around him an artificial world lacking in reality.

The resources and the work at the community level, if it is encouraged and formed, can provide the major part of the support that is needed by the families and the children to overcome the difficulties which result from the impairment.

The variety of categories of individuals that could be in charge of the initial educational process in the rural areas should receive, certainly, a basic, practical and functional training, that permits them to use basic techniques, employ and produce didactic material and make adequate use of the resources at their disposal.

A topic for another paper, since time does not allow it now, could be to establish minimum guidelines and the contents of information to give to these "substitute" teachers.

To end, I find it necessary to point out that programs of this nature must be administered by the school or the principal institution in the field of education for the visually impaired in the country or province, an institution that could set objectives, point out models for action, evaluate the results, and orient and implement the necessary changes. It will be necessary to work with national, provincial, and communal entities, with health centers, etc. in order to look for the most economic, most effective, and rapid way of providing the best and most efficient service.

CONCLUSION

1. Education should not be the privilege of a few visually impaired children; it must reach all, whatever their origin and condition might be.
2. The resources and the work at the community level, if well directed and encouraged, can provide the major portion of the support needed by families and the child to overcome the difficulties resulting from a handicap.
3. Alternative regional programs can be a solution providing basic training to workers from the community who can provide initial services to the families and the children.
4. The alternative programs should be supervised by the main institution with this specialty in a city or a specific country.

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YOU'VE COME A LONG WAY!

Jane Scandary
(U.S.A.)

Two years ago at the conclusion of the First Symposium in Israel in a fit of enthusiasm, Roly Sint Jago opened his mouth and his arms and invited this "family" to Aruba for its next Symposium knowing that there was the intelligence and organizational abilities of Henk de Beijer available to implement his invitation.

It was through the combined talents of these two caring persons that we are here today - and we have witnessed the very human and humane support of the Aruban government to this meeting and to the cause it serves.

The Program Planning Committee met last May, 1982 in Boston with Henk and Tina. It was three days of heavy work and discussion, trial and error planning, scheduling, assigning responsibilities and sharing information and goal setting.

Introduction:

One of the ways to "sum up" or conclude a program of activities such as this is to review the goals established by the Program Planning Committee for the Symposium - I should like to do that briefly with you for the next few minutes.

The first goal of the Symposium was to "create an awareness of the special needs of visually handicapped infants and young children" -

As I listened to the presentations on research and child development, the program already established and the medical sessions, I sensed a deepening conviction - and/or a reinforcement of the commitment to the need for and benefits from early intervention.

As people shared with others their successes and their problems - they gained courage to try new things, gained strength to continue doing what can be for many, a very lonely and isolated job.

But also there was introduced a new and/or deepened awareness relative to the visually handicapped child in developing countries - the multiplicity of the causal factors, the sheer numbers of those so affected - and the political, economic, cultural barriers to habilitation and rehabilitation that are present. This new sense of awareness can be painful - as it does not come by impersonal media (we have all been exposed to that) but it comes from the agony of our friend - our colleague.

There were other awarenesses as - the awareness of technology, its benefits and disadvantages in our lives - how to use it effectively to communicate and demonstrate (if it worked), and how much we still have to practice and rely on the uncommon use of common sense in our lives and work and not be enticed into believing that technology will be the solution of our problems.

A second goal was to share information on needs, problems, programs and services.

Did that happen - I think the amount of discussion before and after meetings, the high attendance at sessions on child development, research, parenting and program materials, the distribution of materials, the ordering of books, the requests for information all exemplify meeting this goal.

Aubrey Webson laid out the problems as he found them in developing countries: 1) infection, 2) malnutrition, 3) ignorance, all compounded by 4) poverty.

Susana Crespo reiterated Aubrey's statements and added findings of her

- own about some of the major considerations in establishing programs to begin to meet the needs of young visually impaired children -
- need to be worked with within the framework of the community in which they live
 - need flexible kinds of programming that can be adaptable to needs of child and culture (fit the program to the child - not child to the program)
 - use existing agencies (schools, health, welfare) rather than trying to create new ones
 - train persons already available and use volunteers to work with the children

Much was said about the use of volunteers by many speakers during these past 5 days. However, I think that it must be mentioned that the whole concept of volunteerism is based upon the idea of "surplus" - time, energy, interest. Surplus meaning that personal and family care and food and water acquisition is such that there is time and energy left over for other things. In many places - if you want to to use volunteers, you will have to first find ways to provide that "surplus" time and energy -

Heather Hewitt presented 5 "Essential Universal Truths" which might possibly serve as a basis for both establishing services as well as evaluating them. I should like to comment that two of the great philosophical questions that have been under debate for centuries are, "Is there any such thing as an essential truth?" and "If there is such a thing as an "essential truth" - is it culturally or universally relevant?" Heather has definitely affirmed that not only do they exist but they exist universally. You may or may not agree - but that does not negate the need for individuals and groups to establish a set of beliefs, a set of standards from which they can evaluate growth/progress.

The third goal: To develop a means of communication among professionals and agencies.

The morning of the first day, I saw people in small groups all somewhat isolated from each other. By coffee break time, the noise level rose and I saw people greeting those they knew and being introduced to those they didn't. I have watched the changing composition of groups at various functions - certainly it is more relaxing and comfortable to be with those whose language you share - but despite language barriers, people were getting to know more people and enlarging their own communication network. I saw addresses being exchanged - the roster of names and addresses will be valued and used. There are publications which provide a communication link - there are also newsletters. I depend more upon personal letters. I answer all letters for information sent me - and I write them. I also collect all my professional journals and publications and every four months I send them to various friends in various parts of the world - Hearing Impaired to Bangkok, Cerebral Palsy and Vision Impaired to Singapore, Administration and Higher Education to Denmark. Joyce Knowles at Castle Priory writes for material, also Israel for Vocational Education, Sweden, from the National Material and Equipment Center, etc. You are your best communication link. I hope that you have taken advantage of this meeting for this purpose.

The fourth goal: "To develop advocacy for visually impaired infants and young children"

I think perhaps this one has been the least addressed - at least publicly. Several speakers mentioned that they felt government agencies should be assuming more responsibility in the problems that have been identified and services needed. Each of you are advocates for visually impaired children - it is part of your professional and personal lives, but I think that times demand a change in the role and function of most of us as advocates.

Story: Three ministers on a golf course - Voice from above: This is no shower. Do you recall another deluge of 40 days and 40 nights? You have been warned - so prepare!" Oh, my God! What are we going to do?

1. Double prayer meetings and organize mass confessionals

2. Set up a lottery to choose ideal couples and buildings

3. Brush up on my life-saving and start swimming courses

This political action need not be overt, but can include assisting in the selection of candidates for office, financial and work support for their election, writing and visiting your local, state, and national governmental representatives inviting them to visit your programs.

(Recent example of its effectiveness: Our legislation which mandated the education of all children was highly threatened by the current administration - the amount of correspondence and contacts from the constituents was greater than anything Congress had ever before seen, and not one Congressman could be found that would support the bill to repeal or alter that legislation.) We need to borrow the tactics that business and industry use to effect legislative change. Get to your decision makers - and keep getting to them. If I had to focus on an item for political action - it would be on identification procedures for early detection of disability among young children. That information is basic for all the next steps.

The fifth goal: To promote research in prevention, intervention and adaptation. The past 20-50 years has seen tremendous technical advancements that have changed eye care and rehabilitation - microsurgery, the laser - to mention a few. However, as has been pointed out, a number of times during various sessions of the Symposium - we have very little knowledge about the impact of visual impairment on the growth, development and learning of a child. There are bits and pieces of research going on but it is isolated and fragmentary. You probably heard more about this subject here than you have since the last Symposium. Research on this population is difficult - not enough persons interested - the population for research is scattered and widely varied - and I'm not sure that we've really identified what we want to look at or what kind of data needs to be gathered. Obviously, to gather the kinds of information necessary to assist us in our work with these very young handicapped children - we are going to have to combine and coordinate efforts with other agencies and organizations concerned with the health, education and welfare of handicapped children throughout the world before we can effectively achieve this goal. Our sessions here on research have made us aware of the great gaps and needs in this area.

Have the goals of the Symposium been met? Each person may have a different answer, but collectively I believe I could say, "Yes" - with some goals met better than others. There was a sixth goal of the Planning Committee - unwritten - that the experience of sharing yourself with this dedicated, enthusiastic, knowledgeable and committed group of persons would enrich your life - and would provide a well-spring of warmth and encouragement to you in odd moments when you are back home and you need to know that you are not alone.

We hope this has happened for you. It has for us. Thank you.

3/4/2011

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